

NCVHS Hearing

Written Testimony from NAPHSIS

Monday, Sept. 11 at 10:30 am - "Current status for vital records: State/local data producers: NAPHSIS and State Vital Health Registrars

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?

The Role of NAPHSIS

Thank you for providing NAPHSIS the opportunity to provide testimony at this important event. On behalf of the NAPHSIS board of director and all of its members, we are extremely grateful that the committee is investigating ways to improve and sustain the national vital statistics system as a whole.

NAPHSIS is the non-profit association of vital records offices in all 57 jurisdictions (50 states, five territories, DC, and New York City). The organization's mission is "To provide national leadership for both vital records and related information systems in order to establish and protect individual identity and improve population health." This document will provide a high level, more national context from the point of view of the association, and its member jurisdictions.

NAPHSIS as a 501c3 nonprofit membership association plays an essential role in representing and advocating for vital records agencies. We not only promote the profession and the importance of the work our members do, but we also act as a convener, collaborator and a clearinghouse of standards, best practices and resources. The NAPHSIS board of directors and robust committee structure guide the Association's work, and inform our advocacy and education efforts.

Advocacy

NAPHSIS works with its partners to educate policymakers about the importance of vital records and infrastructure modernization, and to secure continued federal investment in these priorities and the National Vital Statistics System (NVSS). NAPHSIS promotes the legal and administrative uses of vital records data through its various national electronic systems. The services these systems provide local, state and federal government agencies help reduce identity theft and fraud, and provide timely and accurate exchange of jurisdiction data. The EVVE Fact of Death product is now available to credentialed corporate entities, as well.

NAPHSIS provides national advocacy to promote these services in pursuit of its mission to protect individual identity and improve population health.

Partnerships

NAPHSIS and its members work with a number of partners to improve the availability, accuracy and security of vital records and national health statistics systems. Over the last few years, NAPHSIS has worked with the Robert Wood Johnson Foundation to create a census-tract-level health indicator, facilitated data-linkage projects with the Centers for Disease Control and Prevention's (CDC) Division of Reproductive Health (DRH), the National Violent Death Reporting System (NVDRS), and the Health Resources and Services Administration (HRSA), and provided guidance and technical assistance to many others. NAPHSIS also works with the Environmental Public Health Tracking Network to promulgate best practices for, and awareness of, environmental health tracking efforts within our communities.

NAPHSIS is an active member of the Association of State and Territorial Health Officials (ASTHO) Affiliate Council, and regularly works with its public health sister organizations (Council of State and Territorial Epidemiologists, Association of Public Health Laboratories, Association of Maternal and Child Health Programs) to coordinate cross-sector activities to improve population health.

Through its Corporate Partnership program, NAPHSIS works with companies that provide services and products to vital records offices to define, develop and implement mutually beneficial projects. These relationships have helped build a strong private sector community to support the essential services vital records offices provide and underscore the importance of improving and protecting the data our members collect.

Systems

NAPHSIS also acts as a negotiating body on behalf of the membership for contracts, special projects, data sharing agreements and partnerships with other organizations, creating innovation and economies of scale. NAPHSIS has, for example, developed national electronic systems to facilitate interjurisdictional data exchange and access to birth and death information through its STEVE and EVVE systems.

NAPHSIS developed these systems with and for its members, allowing the flexibility required for a federated system in which each state's laws and statutes govern who can access the data set, when and how. Our national EVVE system helps state and federal government agencies check the validity of birth and death documents and safeguards citizens from those intending to commit identity fraud or acts of terrorism. This system has recently been expanded to include a Fact of Death function, which allows both government and private organizations to search for death records.

Electronic Verification of Vital Events (EVVE) System

The EVVE system, owned and operated by NAPHSIS, allows immediate confirmation of the information on a birth certificate presented by an applicant to a government office anywhere in the nation, regardless of the place or date of issuance. Many federal and state agencies rely on birth certificates for proof of age, citizenship and identification for employment purposes, to issue benefits or other documents (e.g. driver's licenses, Social Security cards, and Passports) and to assist in determining eligibility for public programs or benefits. With the EVVE system, authorized users can submit an electronic query to any participating vital records jurisdiction throughout the country to verify the contents of a paper birth certificate or to request an electronic certification (in lieu of the paper birth certificate). An electronic response from the participating vital records jurisdiction either verifies or denies a match with their official records. The EVVE system will also flag positive responses where the person matched is now deceased—an important aspect for purposes of fraud prevention.

Fulfilling the Need for Death Data

For many years, the only national source of accurate death data was the Social Security Administration's (SSA) Death Master File (DMF), which erroneously made public death records provided to SSA by the jurisdictions in violation of many state laws. In November of 2011, SSA stopped including state protected death records in the public DMF. As a result, the number of death records reported in the public DMF was significantly reduced—by approximately 4.2 million records—and SSA adds 1 million fewer death records annually, rendering the current public DMF increasingly incomplete. NAPHSIS's nationwide system EVVE now offers a Fact of Death product which will include 100% of the nation's deaths.

NAPHSIS launched the EVVE Fact of Death system on March 1, 2017. The EVVE Fact of Death system offers a more complete data set which allows both government and private organizations to search participating jurisdictions' death records to either verify that a death has occurred, or if it *has* occurred, to learn where and when. Users may submit a single query regarding an individual or a batch of queries for millions of records at one time. These queries are checked against the death databases of all participating jurisdictions simultaneously, and the matches are returned to the user.

State and Territorial Exchange of Vital Events (STEVE)

Vital records jurisdictions need a secure and efficient way to send notification of an individual's death to the jurisdiction where that person was born. Since 2009, this transmission of vital event information has been conducted through NAPHSIS's secure, point-to-point messaging system, STEVE. A jurisdiction can use STEVE to send a simple file of all the births and deaths it has recently registered to the CDC's National Center for Health Statistics (NCHS), along with the other jurisdictions. When a jurisdiction uploads this file, STEVE encrypts the file and transmits it to the federal government and the resident jurisdictions at the same time.

This year marked a watershed for STEVE with the development and implementation of a completely new, cloud-based system. The new STEVE system launched in early 2016, with 53

out of the 57 vital records jurisdictions participating from the start. Vital records offices are now using STEVE to send customized vital events data to myriad partners to facilitate newborn hearing screening and immunization registries, voter registration and child support enforcement. Because each jurisdiction sets its exchange rules in the system, STEVE assures full compliance with each jurisdiction's statutes and regulations regarding data release and privacy. The system does all this, while still fulfilling its core function of transmitting event information between jurisdictions and to NCHS to form the basis of the National Vital Statistics System (NVSS).

While supported with federal funds in the past, STEVE was re-engineered and implemented with NAPHSIS dollars and now is being supported solely by the jurisdictions. Another example of a system that supports federal data needs that isn't supported by them in any way.

Legal & Financial Challenges in the Vital Records Office

The nation's 57 vital records jurisdictions work on a daily basis to address the ongoing challenges to maintaining and modernizing the vital records and statistics' data systems. The obstacles for the states to improve their operations are significant and wide-ranging.

Legal Challenges

First, there are statutes in each state that govern how vital records, such as birth and death certificates, may be accessed and how, and by whom, the data may be used. The variances in statutes makes it particularly challenging for the jurisdictions to meet the requests for their birth and death data. A state may have "open records" statutes in which birth and death certificates are created and easily accessible by the public with few restrictions or requirements. Or, a state may have "closed records" statutes with restrictions as to who may access the birth and death certificates, and how the data can be utilized. There are many variations in between. What is considered public information from the birth and death certificates in one state is often considered confidential and protected in another state. This level of variance creates many challenges and confusion for both the potential users of the data, as well as the Vital Records' staff who must protect the information.

Nationally, we have become a patchwork of 57 sets of statutes and rules. However, there is a National Model Law that is revised every 10 – 15 years as a joint effort of NAPHSIS and NCHS. States are encouraged to adopt the National Model Law since it reflects best practices and standards for vital records' administration. But, it is a difficult process for Vital Records' Offices to navigate the many levels of their state governments to propose legislation and advocate for passage by their state legislatures. The topic is often seen as a lower priority when compared to public health legislation, even though vital records and statistics directly impact public health, as well as public safety, security and privacy.

Adoption of the National Model Law by all states would bring increased opportunities for efficiency and collaboration while appropriately protecting the personal information of individuals and families. Though developed in concert with the NAPHSIS membership and

NCHS, the Model Law was never fully endorsed by HHS. This lack of support further disables our agencies to effect change with this important industry standard.

NAPHSIS systems allow the jurisdictions flexibility to participate – or not – as their state statutes allow, to facilitate legal use of the data by both government and non-government entities and for interjurisdictional data exchange. Still, the differences in state statutes – or the interpretation of those statutes – continues to block some jurisdictions from participating fully. This is a significant problem for the data users who want access to ALL 57 Jurisdictions' data. Consistency in the laws AND the implementation and interpretation of those laws would cause significant improvements to the completeness of the data sets AND greatly facilitate access to the data.

Financial Challenges

Although vital records are the primary source of data for calculating health statistics, the jurisdictions are also responsible for registering vital events, providing certified copies and paternity acknowledgments, maintaining adoption records, preserving and securing vital records, and preventing fraud and identity theft. Fees for certified copies and other services partly or wholly fund vital records offices of most states. In Michigan, for example, the processing of vital records requests funds the entire operations of the vital records office, state cancer registry, and state birth defects registry. Vital records fees are usually established by state statute or regulation and not by the office that relies on the proceeds to operate.

The financial challenges experienced by our jurisdictions tend to fall into one of four categories:

- inadequate staffing,
- lack of attention and/or support from IT services,
- lack of sustainable funding for modernization efforts, and
- inadequate – and sometimes unpredictable – funding streams.

The past fifteen to twenty years have been a challenging period for the Vital Records' Offices. They have been working diligently to implement electronic registration systems to collect the birth and death data, create the certificates, and deliver data for analysis and reporting. However, these offices rarely receive new staff to create, implement and maintain those new systems.

In many states, the office staff have worked in their environment for 20, 30, or even 40 years. Their skills were developed during the period of typewriters or basic computers. There are a large number of retirements occurring in these offices, (20-30% per year) which creates opportunities, but also results in a loss of experience and historical knowledge. Only a handful of Vital Records' Offices have younger professionals with background and skills in public health informatics, project management, or newer analytical software packages, including web-based display tools. These skills and experience are critical to improving the efficiency and customer service for both the operational side, as well as the statistics and reporting side. The vital records and statistics field is not seen as a "career path" as much as it was 30 years ago. Hiring

and retention challenges are causing new pressures for Vital Records' Offices. New strategies are needed to attract staff with the needed technical skills, plus the professional interest, to remain in the vital records and statistics field for more than a few years.

In many cases, vital records offices do not have their own dedicated IT staff. IT may be centralized at an agency or state-level, and Vital Records' Offices are struggling to obtain attention and support when considered against all of the other state IT projects. Additionally, many states' IT departments have focused their resources on meeting the national Meaningful Use criteria for immunization registries, state labs, etc., which again has made it difficult to obtain the technical support needed to modernize vital records' operations in many states in a systematic, thoughtful and strategic manner.

As states have modernized their statewide healthcare systems, including public health surveillance systems, with a variety of federal grants, there has been very little of that money trickling down to the Vital Records' Offices for staffing or software systems. In many states, the Vital Records' Offices have experienced significant staff reductions while the responsibilities have continued to increase. Hiring freezes and low wages within the state agencies contribute to a high turnover rate and a troubling lack of technical expertise.

The software systems themselves may be 20 years old and expensive to maintain. The funding that goes directly to Vital Records' Offices from federal agencies has been level or seen only minor increases during the past 10 – 15 years. Also, the portion of state general fund allocated to these offices almost never increases. In many states, the fees collected for copies of certificates are a major part of the operational budgets, but those fees rarely cover the full cost of their vital records' administration. The ongoing budget deficits in many states and the staff recessions or vacancy freezes are major obstacles for implementing new data collection and reporting systems, or to consider business process changes that could improve timeliness, accuracy and completeness of the birth and death data.

Interoperability

All of these challenges impact our membership's ability to participate in data exchange and interoperability. As resources (human, financial and otherwise) dwindle or never increase, it becomes increasingly important for NAPHSIS and its members to participate in cross-organizational partnerships and workgroups like the Joint Public Health Informatics Task force which was just defunded a few months ago. These collaborations break down silos within the industry and are essential to all of our constituents who can't be everywhere in every meeting 100% of the time. CDC is currently working to find additional funding for JPHIT, but support from the NCVHS community would help solidify and extend the impact of this group.

Another issue at the heart of the NVSS is the way these systems are funded, or not funded. The enormous price tag of developing and implementing Electronic birth and death registration systems can vary between 3 and 5 million per state per system. And development is just one

part of the price tag. Each system has its own lifecycle and requires human and financial capital to support them. To upgrade them, to make them interoperable with other systems requires long term, sustainable funding, not one-time investments with year-end dollars.

Data Users

Vital records and their statistics are essential to nearly all parts of the federal government, as well as state-level government, advocacy groups, medical researchers, genealogists, non-profit and for-profit organizations, and the public. But, without question, the biggest users of the data are federal agencies. And, as the largest users, there needs to be adequate financial support provided by the federal government to ensure that the vital records' data will continue to be available in a timely manner and delivering accurate and complete information.

The biggest use of the states' data is the death certificate. It is critically important to know when someone has died so that federal and state benefits can be concluded, to ensure the identity cannot be utilized by others to commit fraud, and to provide timely benefits to the next of kin, such as insurance benefits or pensions. This creates a critical need for regular, ongoing updates of death records to the Social Security Administration, Office of Personnel Management, Internal Revenue Service, Department of Veterans' Affairs, Department of Defense, the Centers for Disease Control, and the Centers for Medicare and Medicaid. This names just a few federal offices; there are a dozen or more that could be mentioned.

In addition to the need for timely and accurate death certificate information, there is also ongoing need for birth certificate data. The Centers for Disease Control are a primary user for purposes of tracking the health of our newborns and mothers, but some of the data is also serving a real-time surveillance role, such as monitoring for indications of Zika-related birth defects. The timely and accurate availability of birth certificate data is also important to the Social Security Administration so that Social Security Numbers can be issued for newborns to prevent other parties from filing a request for an SSN in the name of the child.

There are many other examples that we could provide for how birth and death certificate information are widely used by federal agencies, but these are some of the most visible and important activities.

Outside of federal government, there are hundreds, if not thousands, of organizations that rely on birth and death certificate data. As previously mentioned, there are state agencies, medical researchers, and many types of businesses with legitimate and important operational needs for the data. Their access and use of these data are often detrimentally impacted by the limited resources, technology, or statutes in each state. In some states, the Vital Records' Office can charge for their time to respond to birth and death certificate data requests. In many states, they cannot charge at all.

The most common scenario in which a Vital Records' Office cannot charge for their time is when it involves a sister agency, such as a state's Department of Motor Vehicles Office. DMV is an excellent example of where federal requirements on driver bureaus to validate birth certificate documents is creating pressure on the Vital Records' Office, but without any funding to support the extra vital records' staff that are necessary to meet that demand.

Another example is the Department of State. Their agency conducted checks against the Michigan vital records' databases over half a million times last year. They did not, however, pay any service charge for what is considered a critical activity to meet federal Real I.D. legislative mandates.

These types of federal requirements that impact state agencies very often require access to verify vital records' information, but this is rarely recognized when legislation or rules are written, or when funding is obligated. The burden falls onto the shoulders of the shrinking Vital Records' Offices to help their sister agencies meet those federal mandates, but without any additional resources. This can impact the overall quality and timeliness of vital records' data, and thereby undermine the activities and usefulness of those federal requirements.

At the federal level, some unfortunate language was included in the Social Security Act 205 R that allows the Social Security Administration, which has a contract with each state under the Enumeration at Birth program for the provision of birth and death data, to utilize that state data to produce what is known as the "Death Master File" or DMF for short. The contracts that SSA has with each state explicitly forbid SSA from reselling the states' birth and death data because it is recognized that the states are the owners of the certificate information. However, the Act does allow SSA to share the file with other "benefit agencies." For example, CMS and similar agencies are receiving access to the full DMF to support Medicare and Medicaid activities, but without providing any financial support to the states' that produce the data. Again, zero compensation to the states for collecting and providing what is clearly considered as mission critical information for the federal government.

Additionally, there have been many attempts within the federal government to broaden that access to the DMF to include any government agency – not just "benefits agencies." This is an issue that the states and NAPHSIS have pushed back on since it would open the door to all birth and death certificate data becoming freely available to the country through these other agencies.

Conclusion

The breadth, backgrounds and functions represented by the participants at this hearing is clear evidence of how important vital records data is to every part of a well-functioning government and to the health and well-being of its populace. The burden of supporting the system should not fall to NCHS alone, and it should not fall to the administrative fees we charge our citizens

for what is a critical and essential part of their families' lives. Yet, this is the model that has developed.

The National Vital Statistics System includes every function of the vital records office. One does not exist without the other and the system must be funded that way. The NVSS must be funded in a more sustainable, more cooperative way; across the federal and state agencies that use the data. Not just on the public health side, but on the administrative and fraud prevention side as well.

NAPHSIS has built the infrastructure to deliver the data and the right pricing structure to be the solution to many of the problems detailed here. To support the NVSS, federal and state agencies should use the systems NAPHSIS and its members have developed. We ask that the Committee strongly support a mandate for federal agencies to use (for a fee) these systems and advocate for more consistent legal statutes that will allow jurisdictions to participate fully. With this leverage, these electronic systems will be able to quickly evolve into the robust, timely, integrated, sustainable, multipurpose information system that produces timely data and information flows.