



September 11, 2017

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

Comments from:

Association of Maternal and Child Health Programs (AMCHP) as State User of Vital Statistics

Presented by:

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The Association of Maternal and Child Health Programs (“AMCHP”) is pleased to respond to the request of NCVHS to participate in the NCVHS hearing on September 11, 2017 on the topic of “Next Generation Vital Statistics: A Hearing on Current Status, Issues and Future Possibilities” by providing the following written testimony.

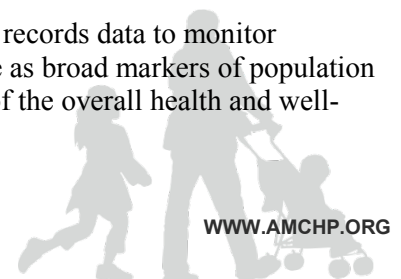
AMCHP is a national resource, partner and advocate for state public health leaders and others working to improve the health of women, children, youth, and families, including those with special health care needs. AMCHP's members come from the highest levels of state government and include directors of maternal and child health programs, directors of programs for children with special health care needs and other public health leaders who work with and support state maternal and child health programs. Our members directly serve all women and children nationwide, and strive to improve the health of all women, infants, children, and adolescents, including those with special health care needs, by administering critical public health education and screening services, and coordinating preventive, primary and specialty care. Our membership also includes academic, advocacy and community based family health professionals, as well as families themselves. As our member programs largely represent public health staff who are working to improve the health of women, children, youth, and families every day, they are directly impacted by the availability of timely and high-quality vital records data.

These remarks address the questions posed by NCVHS for state users and are organized into three main sections:

1. Data use and the importance of vital records
2. Current experience with vital records
3. Data sharing, transmission, and protection

What do you use the data for? Why are they important?

Broadly speaking, state Title V/Maternal and Child Health programs utilize vital records data to monitor population health statistics such as mortality and fertility rates. These rates serve as broad markers of population health. For example, the infant mortality rate is often cited as a general marker of the overall health and well-being of a community.



Vital records can also describe the health of specific populations. For example:

- Death certificates capture recent pregnancy status, allowing for the calculation of maternal mortality rates. These rates can assist public health stakeholders in identifying opportunities for interventions that reduce death associated with childbirth.
- Birth certificate data can aid in determining the prevalence of congenital anomalies (“birth defects”) and provide information about maternal/fetal conditions during the antepartum, delivery, and immediate postpartum periods, including: method of delivery; use of assisted reproductive technologies; maternal behaviors/conditions (i.e., smoking, entry into prenatal care, adequacy of prenatal visits); and infant status at birth (i.e., Apgar score, birth weight, gestational age).
- Vital records also aid in identifying disparities within a population. For example, life expectancy may vary by age, race, or both.

Statistics calculated from vital records data are incorporated into accountability metrics associated with federal and state grants. For example, the Title V Maternal and Child Health Services Block Grant contains a variety of state and national performance measures that allow states to determine the impact of their programming and policy efforts. Vital records data often provide the backbone for calculating these metrics.

Vital records data also inform our understanding of the social determinants of health (the conditions in which people live that influence their health outcomes). For example, birth certificates contain information on maternal education and the payer source for the birth hospitalization. Linked with other place-based information (such as poverty rates, crime rates, and area resources), public health programs can gain a richer awareness of the factors underlying the health of a given community.

State health departments and other stakeholders use vital records data for health planning. In particular, population projections obtained through analysis of birth and death rates influence resource allocation (such as determining the need for specific medical resources through certificate of need determinations).

Federal and state agencies also use vital records data for verification. Using the Electronic Verification of Vital Events (EVVE) system, authorized agencies can verify vital records data for employment purposes, to confirm identity, or for verification of eligibility for certain programs.

While incredibly useful, vital records data are even more useful when linked with other data. As an example, the Tennessee Department of Health (TDH) matched birth certificate data with medical claims data from the state’s Medicaid program and educational outcome data from the state’s Department of Education. This linked dataset allowed TDH epidemiologists to identify educational outcomes associated with a diagnosis of Neonatal Abstinence Syndrome (NAS) in infancy. The incidence of NAS has increased significantly in Tennessee and the rest of the nation over the last decade, largely related to the misuse and abuse of opioid pain relievers. This novel analysis of educational outcomes for NAS infants, the first of its kind, advances the evidence base on this topic and helps identify the “downstream” impact of this perinatal condition.

Ongoing analysis of vital records data also allows for the identification of emerging topics. These are topics that may vary by time and place and that warrant further public health attention or action. Examples include:

- Death certificate data can be used to identify suicide trends among adolescents and young adults
- Birth certificate data can be used to monitor the incidence of certain birth defects associated with exposure to Zika virus
- Death certificate data can be used to monitor the rate of drug overdose deaths

What is the current “experience” with vital records?

The current “experience” with vital records varies greatly across the country. While some states have fully implemented electronic birth and death registration systems, others still rely on the submission of paper birth and

death certificates that are then manually entered into electronic databases. States with fully electronic systems are able to acquire vital records data more quickly and with more accuracy than those using paper systems, which rely on physical transmission of documents and manual entry of data, which introduces the opportunity for human error.

Regardless of whether a state is using an electronic or paper system, the quality of vital records data is only as good as what is entered by users such as birth clerks, physicians, and funeral directors. Data entry often starts outside of health departments, and the quality of the data is dependent upon the skill and experience of those entering the data; some of these positions have high turnover, requiring frequent re-training and transfer of procedural knowledge. Even when those entering data are skilled, they may be limited by the quality or completeness of information available to them (such as from medical records or facility worksheets used to complete birth certificates).

Even when timely data is available, comfort with use of “provisional” data varies by jurisdiction. This may be due, in part, to the broader public’s understanding of the nature of provisional data and the propensity for such data to change. Some public health officials have utilized provisional data to create more timely reports to inform the development of policies/programs or understand impact of policies/programs more readily. Still, others are reluctant to release provisional data because of the fear that those viewing the data may not understand why subsequent reports of the same data may vary with time.

The current vital records experience is also influenced by a changing legal landscape that has introduced complexities in traditional nomenclature. In some jurisdictions, systems need to be changed to reflect updated laws regarding marriage and adoption. Additionally, as reproductive technology advances, appropriate documentation of relatively novel birth circumstances can prove challenging. For example, in the case of surrogate birth using a donor embryo, the “maternal history” of two individuals might well be necessary—the egg donor and the gestational carrier. An additional layer of complexity might be added in the case where a third woman adopts the infant at birth. While this example may seem atypical, these cases are not rare and pose challenges to documentation, as traditional vital records have allowed for one name to be documented for the “mother” and “father” on a birth certificate.

How does data sharing, transmission, and protection work?

The Health Insurance Portability and Accountability Act (HIPAA) law applies to the release of personal health information. Generally, vital events are not classified as personal health information, and aggregate vital records data are typically broadly available at the national, state, and county level.

State laws further govern what is/is not public with regards to vital records. For example, in the state of Tennessee, all record-level demographic data on the birth certificate are public. All fields on the death certificate, except for the Cause of Death, are public. Other records, such as fetal death and induced termination of pregnancy data, are not public.

Even when state or federal laws restrict the general release of data, sharing of vital records data is allowed under certain circumstances. These include:

- Via publicly available summary reports (example—tables describing birth and death rates by county, age, and sex)
- Through data use agreements with researchers, who are bound by parameters specified in the agreement regarding data use and further release
- Under certain public health surveillance requirements
- After approval by institutional review boards (IRBs)

Vital records data are transmitted in a variety of ways. As discussed in the response to the preceding question, states are mixed in their adoption and implementation of electronic birth and death registration systems. In some

states, birth and death certificate data are submitted on paper forms to city, county, or state health departments, where they are typically entered into electronic databases for storage and analysis. In other states, end users (such as hospital birth clerks and funeral home directors) enter data directly into the electronic vital records system, eliminating the need for paper forms and reducing the time required for manual transmission of forms and data entry.

At the state and national level, vital records data are most frequently transmitted between individual states and the Centers for Disease Control and Prevention, National Center for Health Statistics (NCHS) using the State and Territorial Exchange of Vital Events (STEVE) system. STEVE also allows jurisdictions to electronically exchange vital records data among themselves.

The protection of vital records data is one of great importance. At a physical level, data are protected by storage in locked vaults or through other physical security mechanisms (e.g., paper forms and computers located behind locked doors requiring key entry or other identity verification, such as scanning an identification badge). Password-protected systems, encryption of data, and utilization of encrypted transmission methodologies provide further protection of data via electronic means.

Data release policies also provide protection. As described previously, federal, state and institutional policies govern access to data and requirements for release. Data use agreements also describe the requirements for data security by third partners and outline the consequences associated with data breaches.

Recommendations

There are myriad opportunities for improving the nation's vital records systems. AMCHP recommends these key strategies for strengthening the quality, timeliness, availability, and usefulness of vital records data:

1. Enhance the interoperability of systems containing vital records data. For example, supporting strategies to connect hospital electronic health records with state birth registration systems could minimize the resources required for data entry and improve the timeliness and quality of data entry.
2. Provide additional training and technical assistance for "end users" of vital records systems. One such example of end user would be physicians (who need additional training in the proper completion of death certificates).
3. Invest in funding through grants to states to achieve a base level of vital records data infrastructure and system interoperability.

We hope that these remarks have been helpful, and we thank you for the opportunity to participate in this hearing.

Should the Committee have additional questions or need more information from AMCHP, please do not hesitate to contact us:

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