



NCVHS
National Committee on Vital and Health Statistics

May 21, 2018

The Honorable Alex Azar II
Secretary
Department of Health and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

Re: U.S. Vital Registration and Vital Statistics System – Critical Challenges and Opportunities

Dear Secretary Azar:

This letter conveys one essential recommendation and two reports developed by the National Committee on Vital and Health Statistics (NCVHS) – a summary of the NCVHS Hearing on Next Generation Vital Statistics and a follow up report commissioned by the Committee as a result of the hearing, *“Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue.”* NCVHS is your advisory committee on health data, statistics, privacy, national health information policy, and the Health Insurance Portability and Accountability Act (HIPAA).

Vital records are created and maintained for major life events for individuals, including birth, fetal death, marriage, divorce, and death, by U.S. states, territories, and two cities (New York City and Washington DC). 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. Both systems, referred to as vital records and statistics, play a critical role in public health surveillance, such as the opioid epidemic, and evaluation of the effectiveness of health care and health financing, and are relied on for identity establishment, fraud prevention, research, commerce, and many other important uses.

Stakeholders brought significant concerns regarding the sustainability of the vital records and statistics systems to the Committee’s attention. After undertaking an initial analysis, NCVHS held a hearing in Washington, D.C. last September to review the nation’s existing vital records and statistics systems in an effort to understand and assess the current challenges. The hearing convened experts and stakeholders from the business sector, e.g., insurance and pension industries; Federal, state and local governments, both producers and users of the data; researchers; and other organizations involved either in using or producing these data, to understand the critical challenges currently being experienced and suggested paths forward.

The summary of the full hearing, “*Next Generation Vital Statistics: A Hearing on Current Status, Issues, and Future Possibilities*,” is attached.¹

Numerous testifiers spoke to the multitude of uses and users of vital records and statistics, the extent to which was surprising to all stakeholders who attended. At the hearing conclusion, the Committee discussed initial next steps, identifying an immediate need for a better accounting of the uses and attendant challenges. Subsequently the Committee commissioned the report “*Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue*,” which was completed in January 2018 and also is attached.²

The Committee identified five essential findings as a result of conducting the hearing and commissioning the follow-up report:

1. The vital records and statistics systems are the data foundation for public health surveillance, population estimates, identity establishment and verification, death notification and fraud prevention.
2. The vital records system is comprised of 57 different jurisdictional vital registration systems, many of which use outmoded practices and systems, magnified by the differences in laws and policies. Its funding is insufficient to support development to make improvements.
3. The vital statistics system is challenged by the data quality, completeness and timeliness of the jurisdictional vital records systems. Its funding is purpose-specific, resulting in both redundancies and gaps in coverage.
4. Individuals, Federal, State and local agencies, and non-governmental organizations rely on these data to carry out essential functions, some of which are critical to national security. Many public and private users benefit from and significantly rely on vital records data, but relatively few of them directly fund the system.
5. Relatively little is known about the actual functioning, funding, and long-term stability and viability of the vital records offices and vital statistics programs—both individually and as a whole—that collect, manage, archive, and make available vital records and statistics.

The Committee would like to draw your attention to the following two critical points:

¹ [Next Generation Vital Statistics: A hearing on Current Status, Issues, and Future Possibilities](#). Washington, DC: NCVHS, May 2018. Available on the NCVHS website.

² NCVHS. [Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue](#). Washington, DC: NCVHS, January 2018. Available on the NCVHS website.

1. Given the significance of the vital records and statistics systems, more federal attention needs to be paid to this critical national infrastructure.
2. Federal leadership is needed to work closely with states, jurisdictions and Federal agencies to:
 - a) Convene the multiple stakeholders to modernize the federated vital records and statistics system;
 - b) Develop business models to better align payment with uses and distribution of payment to cost centers;
 - Systematically obtain information from each jurisdiction that maintains its own vital registration system on costs, revenues, distribution of revenues and relevant laws and statutes to inform this work;
 - c) Modernize laws, technology and process related to vital records and vital statistics; and
 - d) Train people collecting and contributing vital records data and credential the jurisdictional vital registration systems.

Given the urgency of the situation, the Committee recommends that you make modernization of the system a priority.

The Committee is grateful for the opportunity to study this essential U.S. infrastructure and contribute to its future viability. We are available to engage with the Department in any way helpful while next steps are being considered. NCVHS appreciates the opportunity to support HHS efforts to advance the health system and to working with the Department to shape future efforts.

Sincerely,

/s/

William W. Stead, M.D., Chair
National Committee on Vital and Health Statistics

CC: HHS Data Council Co-Chairs
U.S. Surgeon General
CDC Director
SAMHSA Administrator

Attachments:

- 1) Next Generation Vital Statistics: A Hearing on Current Status, Issues, and Future Possibilities
- 2) Vital Records and Vital Statistics in the United States: Uses, Users, Systems, and Sources of Revenue