Testimony to the National Committee on Vital and Health Statistics, hearing on Next Generation Vital Statistics, September 11-12, 2017[1].

Presenter: Eric Hughes, PhD; Project Lead, Modernizing the National Vital Statistics System; CMS Alliance to Modernize Healthcare (CAMH) Federally Funded Research and Development Center (FFRDC); Chief Architect, The MITRE Corporation

Background

The National Vital Statistics System, NVSS, is a lasting, successful example of inter-governmental sharing of data about vital events – births, deaths, marriages, divorces, and fetal deaths[2]. These vital records, and particularly mortality data, are essential to planning and response to important health issues, such as response to the opioid epidemic, disaster planning, cancer research, and preparing for a future influenza pandemic. Since 1979, the National Center for Health Statistics (NCHS) of the Centers for Disease Control and Prevention (CDC) has provided the National Death Index (NDI) for eligible health researchers to determine mortality outcomes for study participants. Great strides have been made in strengthening NVSS to improve the health security of the nation. The 57 jurisdictions that register deaths in the U.S., in collaboration with the National Association of Public Health Statistics and Information Systems (NAPHSIS) and NCHS, have significantly improved timeliness of reporting of mortality data, increasing eight-fold the percentage of deaths reported within ten days of the event over the last seven years[3]. This has allowed NCHS to report on influenza deaths within three weeks of the event[4], which might help identify an emerging pandemic, and to report quarterly statistics on leading causes of death, such as drug overdose and heart disease[5]. At the same time, the jurisdictions have widely-varying capabilities to register deaths and report deaths to NCHS, with 6 states still lacking an electronic death registration system as of October 2016 and several states capturing less than 75% of deaths using an electronic system[6].

Mortality data have informed the response to many important public health issues. Mortality data have shown the rapid rise in deaths due to opioids, and characterized the epidemic by the

---

[1] **Approved for Public Release; Distribution Unlimited. Case Number 17-3149**

[2] National Vital Statistics System website: https://www.cdc.gov/nchs/nvss/index.htm

[3] D. Atkinson, Presentation at the NAPHSIS Annual Meeting, 2017. The percentage of deaths reported within 10 days of the event grew from 7% in 2010 to 56.5% in the first 5 months of 2017.

[4] CDC, Weekly U.S. Influenza Surveillance Report, accessed at https://www.cdc.gov/flu/weekly/index.htm. State-level data available at https://gis.cdc.gov/grasp/fluview/mortality.html.

[5] NCHS, Vital Statistics Rapid Release, accessed at https://www.cdc.gov/nchs/products/vsrr/mortality-dashboard.htm.

[6] NAPHSIS, Information Systems for Vital Records Stewardship, section on Electronic Death Registration Systems, accessed at https://www.naphsis.org/systems.

state where the death occurred and by the sex, age, and race and ethnicity of the decedent[7]. Vital records help regions track the effects of a disaster, improve communications with affected populations, and plan for future events[8]. CDC is linking vital statistics to data about cancer cases to connect changing rates of cancer incidence to rates of deaths, broken down by state and type of cancer[9]. The NDI has been used over 800 times to study issues such as mortality risk among different occupations, effectiveness of surgeries, costs associated with end of life care, and mortality risks for vulnerable populations like children with developmental disabilities and psychiatric patients[10].

Mortality data are also needed for administrative purposes, including prevention of identity theft and other forms of fraud, disbursement of life insurance and other benefits, and management of lists of participants in programs such as veteran's benefits, healthcare providers' electronic medical records systems, and state voter registration. NAPHSIS and the jurisdictions have established the Electronic Verification of Vital Events (EVVE) Fact of Death system to address these important needs and generate further revenue for the vital records ecosystem[11].

Problem
Despite this progress, many efforts to improve health currently lack the insights into outcomes that could be provided by a comprehensive mortality data source like the NDI. Timeliness of mortality data still falls well short of NCHS's goal of 80% of deaths available within 10 days of the event. This is particularly true for important causes like drug overdoses, which require time for testing and investigation. For example, at the time of this writing, ongoing efforts on the opioid crisis are using 2015 mortality data, because final 2016 data is not yet available[12]. Questions have also been raised about the quality of cause of death information – one recent study found significant errors in half of the death records reviewed, with 9% requiring correction[13]. NCHS has established goals to minimize the number of records with under-

---

[7] R. A. Rudd, et al., Increase in Drug and Opioid-Involved Deaths – United States, 2010-2015, Morbidity and Mortality Weekly Report, December 30, 2016. Accessed at https://www.cdc.gov/mmwr/volumes/65/wr/mm655051e1.htm.

[8] CDC, Health Studies Branch (HSB), Disaster Epi: HSB Staff's Field Experience Boosts National Data Reporting. Accessed at https://www.cdc.gov/nceh/hsb/success_stories/experience_leads.htm.

[9] CDC, United States Cancer Statistics: Data Visualizations. Accessed at https://nccd.cdc.gov/USCSDataViz/rdPage.aspx.

[10] NCHS, National Death Index – How are NDI data used? Accessed at https://www.cdc.gov/nchs/data/factsheets/factsheet_ndi.htm.

[11] NAPHSIS, About EVVE Fact of Death. Accessed at https://www.naphsis.org/evve-fod.

[12] Commission on Combating Drug Addiction and the Opioid Crisis, Interim Report, July 2017. Accessed at https://www.whitehouse.gov/sites/whitehouse.gov/files/ondcp/commission-interim-report.pdf.

[13] L. McGivern, Vermont Cause of Death Audit Study Findings, presentation at NAPHSIS Annual Meeting, June 2017.

specified cause of death, and for overdose deaths to ensure that specific drugs are mentioned[14], but more is needed. The funding that has enabled the progress to date is of limited duration and does not pay for the modernization that is needed for public health.

Most states have limited means to modernize death registration systems and processes. States receive funding from NCHS and to varying degrees from state appropriations, but rely heavily on fees for certificates to acquire and maintain electronic systems. Modernization of state death registration systems is needed to address timeliness and data quality issues limiting the value of the information used for public health response, yet may be difficult for the states and NCHS to afford. Despite the progress made by health researchers using NDI and with EVVE Fact of Death becoming available for administrative uses, there are still many important health issues for which comprehensive mortality data is generally not used, including healthcare quality measurement and improvement, post-market surveillance of new drugs and medical devices, and tracking and improving patient safety. More timely and higher quality mortality data would also have significant utility in areas such as cancer research, influenza surveillance, and disaster preparedness and response.

Although NDI has helped advance health research, the cost to use NDI is high compared to other health research data sources, which limits its application to important health issues. NCHS maintains NDI on behalf of the jurisdictions, who own the data, and the fees to use the system are set by agreement with the jurisdictions and NAPHSIS, last revised in 2004[15]. From our discussions with state vital records offices, all sources of revenue are important, though the revenue generated by NDI represents only a small fraction of their budgets.

Call to Action
The NVSS requires a new business model for NDI and investments in modernization of state death registration systems to continue to serve the needs of the nation. NDI requires a new business model to attract new funding sources, engage the full range of partners, and build the capacity to apply mortality data to important health issues. CAMH conducted over 50 interviews with over 40 organizations that use NDI or need mortality data for important health purposes, detailing the need to reduce the cost of NDI for health researchers. CAMH analyzed five years of NDI usage data, showing that lowering the cost of NDI to be comparable to systems such as EVVE Fact of Death would put NDI operations and funding to NAPHSIS and jurisdictions at risk, and that a small number of organizations' use of NDI generates the majority of NDI revenue. To implement a new business model for mortality data, a public-private partnership should be established by NCHS, NAPHSIS, the jurisdictions, and other key stakeholders in mortality data. This partnership should focus on enhancing the readiness and capacity of localities, states, and the nation to address key health issues and crises. The partnership should include working groups on specific health crises, as well as groups focused

---

[14] D. Atkinson, Vital Statistics Cooperative Program, presentation at NAPHSIS Annual Meeting, June 2017.
[15] NCHS, National Death Index User Fees, effective October 1, 2004. Accessed at https://www.cdc.gov/nchs/data/ndi/ndi_user_fees_worksheet.pdf.

on building the infrastructure needed and to modernize death registration systems and processes. The partnership should be created with the means to apply a variety of funding sources to sustain and modernize national and state systems and processes.

Modernization of death registration systems is required to provide the timely, high-quality data needed to address public health issues. CAMH reviewed eight jurisdictions and convened a working group with broad stakeholder participation in January 2017 to envision the capabilities of a next-generation electronic death registration system (Next Gen EDRS). CAMH has developed a prototype Next Gen EDRS, available to vendors and all interested parties[16], and is working to assist states in the process of acquiring their first EDRS, and to pilot Next Gen EDRS services to demonstrate their value in addressing public health issues. A Next Gen EDRS must support electronic exchange of data with other systems in the death registration process, including electronic health record systems, case management systems used by medical examiners and coroners, and systems used by funeral homes. A Next Gen EDRS should support analysis of death records and support response to public health crises at all levels of government. These advances must be sustained and improved over time with input from the diverse spectrum of stakeholders, as will be possible with a public-private partnership.

Conclusion
Vital records, particularly mortality data, must be modernized to provide essential insights needed to improve the health and security of the nation. A public-private partnership, implementing a new business model for the National Death Index and mortality data, is needed to fund and sustain these efforts. Next-generation systems must be developed, used, and evolved over time to meet the public health needs of the future.

---

[16] CAMH, Nightingale Next Gen EDRS, posted June 2017. Available at https://github.com/nightingaleproject/nightingale.

The Mortality Data Cycle is Complex

COMMUNITY   STATE   NATIONAL

Mortality Data Uses

Medicaid
Voter Registration

Research
Public Health
Population Health

Insurance
Identity Theft

Deceased
Family
Estate

Registration:
Registrar
Medical Certifier
Funeral Director

EDRS

Coding and
Processing

Mortality
Statistics

National
Death
Index

NCHS