Questions and Answers

Q: I work on a multi-state research project, and have had some challenges with getting timely birth certificate data from a couple of states where cleaned data are available more than 12 months after the calendar year. While preliminary data are available, a few of these states will not release these data to researchers. What are some of the reasons for electing to do so? Is there a push from NAPHSIS to make preliminary data available to researchers?

A: (Patricia Potzrebowski) Each state knows its own data best, and they may be aware of particular problems or biases that may make preliminary data less reliable. Or they may be concerned about small numbers of events. Perhaps it would be good to have a meeting with the state vital statistics staff to ask them this question directly.

The NAPHSIS Statistics Committee has a subgroup that is working on developing best practices for the states to make preliminary data available. That said, however, there is tremendous variation among the jurisdictions with respect to registration practices that may impact a state’s ability to release preliminary data.

Q: How are data not available from institutional settings (e.g., home births, deaths which have not been attended) included in these statistics?

A: (Patricia Potzrebowski) All births and all deaths that occur within a particular state are required to be reported within a set time period to the state vital records office. In some states, home births are reported as fast or faster than hospital births, while in others they may lag to some extent. Unattended deaths require the coroner or medical examiner to file the death record, and some, but not all, of these deaths will be reported as “pending” with the cause to be determined later, due to ongoing investigation or waiting for lab tests (e.g. toxicology). These and other special cases may impact the accuracy and completeness of the preliminary statistics, which is why developing preliminary statistics is an art as well as a science, as there is a need to balance completeness of the data file (which impacts the reliability of the statistics) with how quickly the preliminary statistics can be calculated and released.

Q: How will increased use of electronic health/medical records influence electronic reporting of deaths?

A: (Patricia Potzrebowski) EHRs may or may not improve timeliness of reporting of natural deaths that occur in medical institutions – hospitals, nursing homes, hospices – but will probably not have an impact on coroner/ME cases. Even in institutional deaths that are due to natural causes,
the physician will most likely need to establish the sequence of events that resulted in death, because that sequence may not be the same as the reason the person was hospitalized.

Q: What are your recommendations or justifications for Epi’s to access STEVE? Are there any restrictions on jurisdictions or state? Are there interpretative deficiencies due to niche knowledge?

A: (Patricia Potzrebowski) That they have a legitimate public health use for the data (which they should specify) and need timely information as quickly as possible so that they can take action. No re-release of PII is a common restriction. Each state may have its own additional restrictions.

(John Paulson) Our epidemiologists in Ohio do not access STEVE as they are getting the analytical datasets from our VS office. STEVE can help to get records from other states for specific uses when the epidemiologist’s home state does not have the needed information or when agreements with the other states bars the sharing of those specific data elements. Users will need to understand the standard layouts used in STEVE and the meaning of the variables.

Q: At least in IA, death records obtained via interstate exchange are not available to researchers, despite approval of application for data access. What is the reason for this?

A: (Glenn Copeland) States share records with each other when someone dies outside their state of residence and/or their state of birth. These exchanges are conducted under the terms of a data use agreement that restricts the use of the records and data by the receiving state. Basically, though the records are shared for statistical use (to enable accurate resident statistics) and for fraud prevention (to flag birth records of deceased individuals) other uses beyond these two primary functions are restricted and remain the prerogative of the sending state.

Q: Do death records go directly from NCHS to NDI or do they go back to the states before submission to NDI?

A: (Glenn Copeland) Death data forwarded by the states to CDC are sent from the state directly to both entities at NCHS as NDI is operated by NCHS. Many states send a single death file that is split and distributed for NCHS statistical use and NDI inclusion. Others send these as distinct files. In either case, the data traffic is all one way.

Q: Isn’t there a requirement that deaths are reported in a certain number of days? Like a week?

A: (Glenn Copeland) Yes. I expect all states require a death registration within a specific number of days or even hours. The current model law indicates a filing should occur within 48 hours. While there are circumstances that can legitimately delay a 48 hour filing, other issues are the primary source of delay in getting electronic death data.

In a typical scenario a death record filed on paper is presented to a local registrar who will hold the record for a period of time. In Michigan, they package death certificates for shipment to the state at the end of each month. So, the filing could have occurred 30 days before being shipped...
to the state. Once received, the records are reviewed for errors, organized, inventoried and coded preparatory to numbering, filming and keying. Once prepared they are sent for data entry and returned with associated data files. All the while, the clock is ticking. In Michigan, these steps result in electronic data being available for paper filings in an average of 134 days.

The grand bonus we receive with an electronic death registration system is that the death data is readily available within hours to days of the death in most cases. That is the reason we are striving so hard to encourage adoption of this new alternative way to register a death.

Q: California physicians almost always attest via fax directly back into the EDRS, not by voice. And before the attestation, there is plenty of back-and-forth for correction of causes.

A: (Glenn Copeland) How to get timely and accurate medical information is a challenge to all of the states. A focus on this is needed. Learning from each other on efficient and effective methods to engage, interact with and, perhaps, educate certifying physicians is important and still needs work.

Q: Does the fetal death reporting system utilize any of the death reporting architecture used for post-fetal deaths?

A: (Glenn Copeland) This varies by state. In Michigan, fetal death reporting is accomplished through our live birth reporting system. This is generally convenient as most fetal deaths are delivered in hospitals with already existing access to the birth system. Electronic fetal death reporting is not universally available, though. The rarity of these cases coupled with the considerable expense to develop electronic systems often prevents a state from standing up a Web based approach.

Q: How preliminary are your "preliminary datasets"?

A: (John Paulson) Our warehouse data updates every weekend. It updates from a copy of our production application data that is refreshed overnight every night. So our warehouse can be up to 8 days behind our production application database. Once updated in the warehouse the new data can be downloaded and is used in reports/charts/maps. We simply flow the refreshed data into the warehouse each weekend and that is when the data is available. So on a Monday morning you could possibly be seeing births from the previous Friday. There is probably a 3-5 day average lag time from the time of birth to the record getting keyed into our production birth application.

Q: Is there a fee for partners (other than states) to access information through STEVE?

A: (John Paulson) We do not have a fee in Ohio for our users.

Q: Where can you find technical information about STEVE files?
A: (John Paulson) The National Association for Public Health Statistics and Information Systems (NAPHSIS) is a good source of information: https://naphsis-web.sharepoint.com/Pages/AnOverviewoftheSTEVESystem.aspx

Q: Do any of the presenters have an estimate on the average time for reporting of fetal deaths?

A: (Glenn Copeland) The answer to this question will be very state specific. In Michigan, the average is under 30 days. These reports are quite problematic though and require routine monitoring to ensure reports are not being missed. Unlike birth and death registrations, there is no driving need for a legal document on these events. This combined with the rarity of the events creates a number of problems in the facilities that the state offices must routinely spot and address. Still, a strategy to include fetal death data in any provisional reporting efforts is entirely feasible.

(Patricia Potzrebowski) This varies by state, in part because the requirements for reporting fetal deaths vary by state, but also because fetal death processing may fall behind due to birth and death registration being a higher priority, especially when a state vital records office does not have adequate resources.

About DataSpeak
The Maternal and Child Health Bureau’s DataSpeak webinar series is dedicated to the goal of helping MCH practitioners on the Federal, State, and local levels to improve their capacity to gather, analyze, and use data for planning and policymaking. DataSpeak is funded by the Maternal and Child Health Bureau’s Office of Epidemiology and Research under the supervision of Gopal Singh, PhD. This question and answer sheet was created by moderator Sarah Lifsey, MPP.

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