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How Can Vital Statistics Remain Vital for Measuring Health Status in the U.S.? [1]

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[1] The text is presented without formal editing.

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Background:

1. Seven years ago, I wrote an essay about the status of the National Vital Statistics System (NVSS) in the United States at the request of the editors of Preventing Chronic Disease. Much of the essay was about the challenges and promises of automation for the NVSS and its need for change to remain relevant. Let me quote extensively from that essay to provide a baseline for where we were at that time, then provide a status report on where we are now and finally what lies ahead.

2. For more than a hundred years, the United States has operated a decentralized vital statistics system as an essential component of public health. Statistics based on births and deaths registered in the United States are a primary source of data used to track the health status of the U.S. population, to plan, implement, and evaluate health and social services for children, families, and adults, and to set health policy at the national, state, and local levels. Data on access to prenatal care, maternal risk factors, infant mortality, disparities in health status, changes in the rankings of causes of death, life expectancy, years of potential life lost, and other pregnancy and mortality indicators provide the staples for public policy and programmatic debates about improving health and health services delivery. Unlike any other public health data system, the NVSS provides nearly complete, continuous, and comparable federal, state, and local data to public health officials and programs. This strength enables population-based analysis and comparisons to be undertaken at the national, state, and local levels by age, race, ethnicity, and sex. For example, with more than two million deaths each year, disparities in the leading causes of death by race and age can be monitored and compared at the local, state, and national levels. Rare and emerging causes of death can be identified, and using both the underlying and contributing causes of death, the impact of such diseases as hypertension, diabetes, and atherosclerosis on mortality can be measured.

Status of the U.S. Vital Statistics System in 2004:

3. Despite the importance of the nation's vital statistics system, in 2004 the NVSS relied on outmoded vital registration practices and systems, a fact that raised concerns about data quality, timeliness, and the lack of real-time linkage capabilities to other data systems for the more than six million annual vital events. To resolve these issues, vital registration required complete automation at the level of primary data collection as well as changes in the relationships among the providers of source records, the state registration offices, and the National Center for Health Statistics (NCHS). Even though for the previous 20 years, states had been using electronic birth registration systems and this was a significant step forward, states continued to operate dual paper and electronic systems, with the paper record considered the official legal document. To compound these problems, these electronic systems for vital registration were difficult to modify, causing many states to delay implementation of the 2003 revisions to the U.S. standard certificates, which would have provided a wealth of new information.

4. The collection of death information in 2004 continued to be a paper-based process, unchanged at the local and state levels for the last half century. In the U.S., funeral directors are responsible for collecting demographic information on the decedent from the next of kin, while attending physicians, medical examiners, or coroners provide and certify medical information on cause-of-death. Demographic and medical information were brought together manually by passing the paper certificate back and forth; the certificate data did not become computerized until reaching the state vital registration office, sometimes after considerable delay. The lack of automation at the source precluded timely follow-back to improve data quality and did not take advantage of existing internal systems of funeral directors and physicians. Also the Internet was not used for electronic data transfer or systems updates between data providers and state registration offices.

5. To address these problems, the National Association of Public Health Statistics and Information Systems (NAPHSIS), NCHS, and the Social Security Administration developed a partnership to improve the responsiveness of state vital registration and statistics systems. Their objective was to improve the timeliness, quality, and sustainability of these systems by adopting national, consensus-based standards and guidelines, for it was necessary to go beyond modifying existing registration systems. State processes and systems had to dovetail with local data providers' processes and systems. Stand-alone systems and paper-based processes could no longer be considered adequate. An overarching consensus within this partnership was that business practices within state vital records offices and data providers should be documented and then updated to be more efficient and effective in light of new technologies and that these systems should be driven by national consensus-based standards and guidelines. The resulting reengineered state systems would use the 2003 version of the U.S. standard certificates of live birth, death, and fetal death as well as the consensus guidelines. Re-engineered systems would include efficient methods for capturing data, standard data-collection instruments, coding specifications, query guidelines, and definitions, and also Health-Level-7–based standardized messaging. As a national health information infrastructure came together, these reengineered vital statistics systems would need to be integrated with other health information systems, such as those for immunizations, newborn screening, and hearing screening, and with electronic systems used by data providers, including hospitals, physicians, and funeral homes.

6. The national partnership and its consensus process made some notable accomplishments, including the development of functional requirements for reengineered birth and death registration. The consensus national requirements served as the foundation for the design, development, and implementation of reengineered, Internet-based vital records and statistics systems for states. Besides funding, the most daunting challenge remained the automating of reporting of deaths by the thousands of funeral directors and physicians who were still manually providing mortality data to the states.

7. Much needed to be done: 1) States needed to re-engineer their vital registration systems at the source using the internet to its fullest advantage; 2) data transmission standards needed to be developed that would allow for linkage to emerging electronic medical records; 3) a single data transfer system needed to be developed to allow states to quickly transfer to other states out-of-state resident events and vital statistics to NCHS and other Federal agencies; 4) States needed to change their vital registration laws and regulations to support electronic collection and issuance of vital records and 5) NCHS needed to improve its automated mortality coding system

and provide other internet based software seamlessly through state automated registration systems directly to the data providers to improve data quality and timeliness and 6) NCHS needed to re-engineer its internal systems to take advantage of state automated systems by editing at the time of data receipt and move away from annual processing and reporting to year-to-date reporting.

Status of the U.S. Vital Statistics System in 2011:

Internal NCHS Systems:

8. Phase 1 of re-engineering the internal NCHS systems has been completed and is now accepting data transmission from the states. Our goal is the creation and implementation of a secure, module-based interoperable system operating in an SQL Server environment that will: 1) efficiently process birth, death and fetal death records received from the 57 jurisdictions; and 2) enable easy access to and use of the data for analytical and dissemination purposes at any stage in processing the records. We are primarily complete on receipt and editing of data from the jurisdictions and messaging back to them on data quality issues. Much work remains on using the system for mortality surveillance and to improve the utility of the system for statisticians and analysts in NCHS for both birth and death data analysis. The re-engineered system is characterized by the following attributes:

- Contains as many of the validations and edits near the initial point of record receipt as possible;
- Enables the statisticians and specialists to communicate back to the states on the quality of the records within 2 days of their receipt;
- Minimizes the need for human interventions in processing the records from one stage to another;
- Incorporates fundamental techniques and best practices of relational technology, enabling the reduction in both data and process redundancy;
- Able to code at least 90% of the death certificates (both underlying and multiple cause) electronically, with an error rate of 1% or less;
- Of those mortality records coded electronically, able to return the cause-of-death codes back to states within 24 hours of first receipt of the original record at NCHS;
- Enables the statisticians to manipulate the data at any stage of processing the records;
- Able to electronically alert appropriate statistical staff if: (a) known rare causes of deaths or other identifiable events are found in records being processed each night; and/or (b) unusual pattern of health events are occurring or have occurred suggesting that some attention may be warranted; and
- Designed and built with ease of maintenance as a central tenet.

9. Again much remains to be done on making the system more useful to our analytic staff and how we may better transform our organizational structure and responsibilities to take advantage of the technologies we have employed. We also need to continue to improve the throughput of our automated medical coding systems.

Record Exchange System

10. The State and Territorial Exchange of Vital Events (STEVE) System is a messaging application developed by NAPHSIS (organization representing state vital registrars) and funded by NCHS for the electronic exchange of vital event data between jurisdictions. STEVE replaces the current, less secure practice of exchanging paper copies, line lists and printed computer abstracts which most states use today for record exchange. Participation in STEVE is open to all U.S. vital records jurisdictions and Canadian provinces that have signed the Inter-jurisdictional Exchange Agreement administered by NAPHSIS. Currently 16 states have implemented the system with 6 states preparing to implement. Beginning January 2014, STEVE will be the mandatory method for state reporting of births, deaths, and fetal deaths to the National Center for Health Statistics (NCHS).

Essentially, STEVE works like this:

- The sending jurisdiction loads (manually or automatically) a standard file into the STEVE inbox. STEVE continually "senses" and picks up the file for processing.
- STEVE sends the file through a series of "filters" representing the jurisdiction's pre-configured data exchange rules. These filters block out or allow specific data items to be sent to each approved recipient.
- STEVE reads the state of residence in each record to see if external routing is needed.
- STEVE repackages the records into routed, encrypted files and transmits messages to their destinations.
- Files are transmitted within minutes to the receiving jurisdiction's main mailbox. If mailboxes have been set up for public health partners, their files can be automatically routed to those mailboxes.
- STEVE provides tools to extract records from the standard file in comma separated or Excel format for loading (manually or automatically) into the jurisdiction's main vital record database.

State-based Electronic Birth and Death Registration Systems (EBRs and EDRs)

11. States have shown that the development of Electronic Death Registration Systems (EDRs) and Electronic Birth Registration Systems (EBRs) throughout the United States is both feasible and affordable and can significantly improve data timeliness such that mortality and natality reporting can once again be considered an essential component in public health surveillance. Currently 35 jurisdictions have functioning EBRs and 31 jurisdictions have functioning EDRs. Initially these systems slowed down the reporting of vital events but within a year most systems became more dependable and the timeliness of reporting improved. The major stumbling block has been the coverage of certifying physicians in jurisdictions with EDRs. The demographic and registration portion of their EDRs is easily handled by the funeral directors, but participation of physicians in providing cause-of-death information is lacking, partly due to physicians wanting to only deal with one integrated automated medical record system in the documentation and support of their work.

NCHS developed and supported systems for improving the quality and timeliness of mortality statistics

12. A recent evaluation of mortality records found that data input errors and omissions contributed to a large portion of mortality records being rejected by the NCHS automated coding system. This evaluation found that annually about 350,000 of the 2.5 million mortality records processed each year (about 14%) are rejected for a variety of reasons. Of the rejected records, approximately 32% (or 113,000 records) are rejected because of spelling mistakes or unrecognized terms in the cause-of-death fields. Each rejected record requires nosologists to assign the correct code, significantly increasing the cost and reducing the timeliness of processing mortality records. Simply improving the quality of the spelling and minimizing unidentified terms entered into the DVS automated coding system is estimated to increase the throughput of the automated coding system from the current 86% level to our 90% goal, saving over 125,000 mortality records from being coded manually.

13. NCHS is currently developing a system called VIEWS to improve the information that goes into the automated coding systems. The VIEWS validation application is a web service which will have the ability to receive encrypted cause-of-death literals from a state's EDR system. VIEWS can also run in batch mode for non-EDR states, where a file would be uploaded to have the rare cause / validation report run. After receiving a literals file, VIEWS will apply the rules or validations against that file and return in real time any errors or warnings to state EDR and the state EDR will then display any warnings, errors, or user help from VIEWS on the EDR screen in the same format as other edits or messages are currently displayed. The processing of validations will occur in milliseconds and to the end user will appear as if the record is being validated by the state EDR system. Stage 1 of the system will be implemented this summer with pilot states and will provide:

- *Rare Words* – Words that are rarely in a mortality record. These words may be proper English words, but are most likely an error due to the rarity of occurrence.
- *Intelligent Mortality-focused Spellchecker* – A spell check that ranks suggestions for misspellings on most likely candidates, not merely on sound alike operators.
- *Data Validations* – Checks data formats. Line lengths, field lengths, other validations such as dates.
- *Ambiguous Abbreviations* – Abbreviations that can have more than one meaning. (Example: CRF can either be "Chronic Renal Failure" or "Chronic Respiratory Failure".)

14. The next phase will include verifications of:

- *Rare Causes* – Causes of death that rarely occur and need verification by the data provider and/or the state.
- *Causes of Public Health Surveillance Interest* – Death causes of interest to public health that need to be flagged for immediate follow-up by the state can occur (Ex. H1N1).
- *Cause of Death Agreement with Age / Sex* – Checks for correct age and sex agreement, e.g., women with prostate cancer.

- *Trivial / Ill Defined Causes* – This verification would warn the data provider that no cause listed on the record seems to cause death and that more information is needed.

15. An interesting outcome with improved automated medical coding systems has taken place … a sort of "back to the future" approach. Before automated medical coding systems, NCHS manually coded all mortality records in the U.S. We developed automated systems hoping to improve timeliness of coding and speeding- up the training necessary to have a qualified nosologist. Although timeliness and speed of training did not improve as expected, what did improve was the ability to have the states use the automated systems to do the coding and still get comparable coding of records throughout the country. However as the throughput of the coding systems improved, smaller states and then larger states did not have enough records rejected by the system to support trained nosologists. So in 2011 all coding is done once again at NCHS. The states provide us with the medical literals and we run the automated coding systems and then code those records manually that are rejected from the system. We provide the records coded by the system within 2 days (goal is 24 hours) back to the states and those that are manually coded within 12 days (goal is 7 days).

16. To further help the physician and to improve data quality, NCHS and NAPHSIS have developed a web-based tutorial for how to handle specific causes of death. The prototype of this system was developed by New York City and in NYC, physicians must take the tutorial before being allowed to certify a death certificate. We plan to offer this generalized web-based tutorial module to all states this summer.

17. Additionally we have developed HL7 data transfer standards for vital statistics. These standards will allow for the building of electronic medical records containing appropriate data for populating vital records. One state is currently using these standards to pilot data transfers between hospital based electronic medical records and vital records. As automated medical records systems become the norm in the U.S., much more pilot testing of data exchange and transfer needs to be done.

Model Law:

18. Because there is no federal registration of vital events in the U.S., vital registration is directed by state law and regulation. NCHS periodically publishes a Model Law for guidance to the states to help them in the implementation of appropriate vital records legislation. With computerization completely changing the landscape of vital registration, state vital registration laws and regulations need to be modified to account for electronic registration of events as well as meeting growing concerns over the security of the systems and procedures for registering and issuing vital records. To meet these challenges, the Model State Vital Statistics Act and Regulations, last modified in 1992 is undergoing its most significant modification in over 50 years. The draft revision has been developed and just approved by the states at our joint annual meeting earlier this month. This revision will now be reviewed within the Federal government and also through a public comment process and hopefully within the next year will be published for states to update their current vital registration laws to better support among other things, electronic registration activities.

On the Horizon

19. Currently, the process for completing and processing death certificates is still inefficient, slow and costly. For some states a paper based certificate is still in use, while others which use an EDR have the same problem. The knowledge and ability of the certifier to complete the certificate according to the rules specified on the certificate must be followed for the data collected to be accurate. It is widely acknowledged that the current quality of the data collected from death certificates is questionable for completeness and accuracy because the certifier does not understand what is being requested. We are planning to develop a question based system that would be an app link between the information on the physician's electronic health record and the electronic death registration system. This app would move EDRs away from just duplicating the old paper system into real world question-based data collection where the certifier focuses only on his/her medical expertise and the app deals with proper formatting for the death certificate.

20. More than just quicker annual reporting, mortality surveillance also needs to be put in place with the advent of the systems mentioned above. Real time review and parsing of the cause of death literals on the electronic records along with their ICD codes is now in the developmental stages with key staff assigned to this project. Provision of deaths of public health immediacy in real time to state and federal programs is very possible and could be a significant outcome of our automation efforts.

21. Unlike many countries, the U.S. collects considerable medical information on the mother and child on the birth certificate, making it almost a perinatal record. One reason is that although medical claims have been highly automated in the U.S. for some time, medical records have not and thus studies examining factors relating to our high rates of prematurity and infant mortality needed this information to be collected and automated at the registration of the birth. However, once electronic medical records become ubiquitous and collect the information for vitals meeting HL7 standards, perhaps birth records will no longer need to collect all this medical information on each event but use the vital event as a sampling frame to study outcomes of specific births and then pulling appropriate information from the electronic medical record of the mother and infant. We are a long way from this approach but it may be feasible in the next 10 years.

Future Challenges:

22. With the advent of the Internet and the widespread availability of computer power to health care professionals, researchers and the public, vital statistics face a rapidly changing future with respect to data collection and access. The implementation of electronic death registration systems and the automation of cause of death coding, will make it possible to release more timely information on causes of death, as well as to provide day-to-day and year-to-date surveillance of emerging causes of deaths and deaths of acute public health significance. However as the public enjoys an ever-expanding access to data bases on the Internet that can potentially be linked to other data sources, how can confidentiality be protected while, at the same time, provide important vital statistics data to researchers and policymakers? Also with the advent of electronic health records, NCHS is developing national data transfer standards that will allow for the sharing of information between electronic vital registration systems and electronic health records. This effort has the potential to improve the timeliness and data quality

of birth and death statistics and to provide the mechanism to collect other health outcomes related to the vital event. However, will these electronic health record standards be actually followed by vendors of electronic health records systems to the extent that comparable data from medical records can be transferred to the vital registration systems and will data providers provide any more complete and accurate information to the electronic health records than to existing medical record systems both manual and automated? With what has been learned over the last 7 years with EBRs and EDRs, the high cost of maintenance of these state-specific systems, the onslaught of automated medical records systems and advances in web based technologies; it is probably time to develop a core set of registration systems that all states can use but that the Federal government supports. However will states be willing to give up some of their differences to have more efficient and less costly systems is still an open question. Although the future of automation holds many challenges for vital registration and statistics, it also offers the opportunity for vital statistics to become more than just chronicles documenting the past, but the "GPS" of our current health status. I firmly believe the future of vital statistics has never been brighter.