

**HIT Standards Committee
Clinical Operations Workgroups – Task Force on Vocabulary**

Public Hearing- March 23, 2010

Comments: Charles J. Rothwell, Director Division of Vital Statistics, NCHS, CDC

1) What vocabulary subset or value set creation and distribution services do you provide?

The National Center for Health Statistics (NCHS) administers the National Vital Statistics System and publishes national reports and major health indicators based on this system. The vocabulary and data content are specified by the US Standard Certificates of Live Birth and Death and the Report of Fetal Death. For births and deaths these standards began in 1900 and for fetal deaths in 1930. There have been 11 revisions of the live birth certificate, 10 revisions of the death certificate and 7 revisions of the report of fetal death with the latest revision promulgated by the Secretary of HHS in 2003. Since the late 1970's the data content of U.S. Standard Certificates and Reports have determined the electronic data content transmitted to NCHS by the 57 registration areas which will be called "states" (50 states, 2 cities and 5 Territories) and it is the responsibility of these states and not the Federal government to register vital events. We also have been responsible for administering the ICD for mortality in the U.S. since 1900 and we are now using the 10th revision of the ICD which was implemented for all deaths in 1999. We also have developed an automated medical coding system which is able to code automatically over 85+% of all deaths and that system is used for coding of all U.S. deaths and is also used as the core of automated coding systems of many of our international partners. Finally we administer the National Death Index for the states which is used by researchers nationwide to help them with their mortality ascertainment activities.

2) Who uses your services and what is the level of use?

All states use the U.S. Standard Certificates and Reports as a basis for their certificates and reports and their automated data collections systems which are used by hospitals, certifying physicians, medical examiners, coroners and funeral directors to record all vital events (4.3 million births, 2.4 million deaths and 26 thousand reportable fetal deaths). There is some variation from state to state, but for the most part there is a high level of agreement between the data content and specifications of the state certificates and systems with the U.S. Standard. This high level of compatibility is driven by the NCHS contract specifications with states, the states desire to have comparable data for comparison and a long-standing partnership between the States and NCHS. NCHS contracts with states (about \$19 million/year) to obtain their data in a proscribed format and meeting strict data set requirements. The users the data from the National Vital Statistics

system at the local, state and national level are legion and major health indicators provided by the system include life expectancy, leading causes of death, infant mortality rates, fertility rates, teenage pregnancy rates, prematurity rates, methods of delivery, etc.

3) What, if any, additional services and capabilities are in active development?

We are currently in the development of HL7 Standards for births, deaths and fetal deaths with the hope that these standards will be accepted this year. This is a first step toward creating an environment that will encourage data sharing where appropriate between vital record systems and electronic medical records. Most importantly states are continuing to automate and upgrade their data collection systems which are used by their data providers. These systems called EBR's (electronic birth registration systems) and EDR's (electronic death registration systems) are what hospitals, certifying physicians, medical examiners/coroners and funeral directors use to register a vital event and provide the associated medical information relating to the event. These systems along with upgraded systems internal to NCHS will provide for faster registration of vital events and more timely vital statistics. NCHS is also re-engineering its automated medical coding system to make it more efficient and improve its coding capability to code over 90% of all death records. We are currently participating in the WHO process in the development of ICD-11, which will not be implemented for some time.

4) If applicable, what process is used to establish and revise any subsets or value sets that you distribute?

The revision process for the certificates begins with a survey of the State vital registration and statistics executives to determine whether revisions are needed. If the consensus from the States is that the birth and death certificates, as well as the fetal death report, should be revised, NCHS then assembles a panel of expert consultants to evaluate the Standard Certificates and to recommend revisions. The panel includes State vital registration and statistics executives as well as representatives of data provider and user organizations and the panel also receives testimony from outside experts. The report of the Panel is made available to the Secretary of HHS and is used by the Secretary to form the basis of the next revision of the U.S. Standard Certificates and Report of Fetal Death. The Secretary then publishes the new revision to the U.S. Standard Certificate and this new revision forms the basis of the next revision to the National Vital Statistics System. Again it should be noted that States are not required to go to the new revision and in fact there are still states which have not gone to the 2003 revision of the certificates.

5) Based on your experience, what advice would you offer regarding best practices and pitfalls to avoid?

The systems which collect, edit and generate the data need to be standardized and carefully certified. Providing data standards even in detail is not adequate. NCHS was involved with the states, NAPHSIS (National Association for Public Health Statistics and Information Systems) and SSA to develop use case models for web-based EBR's and EDR's and this effort was a success. However it did not have the wherewithal to fund the development of these systems nor to certify the systems developed by vendors actually did what they claimed to be collecting, editing and providing. Many states had significant development and implementation problems which could have been avoided with the development of a core system that could be used by vendors as a starting point for their systems or as a guide to their systems. Also an independent certification process could have helped states discover before implementation if there were any issues with the software being offered and such a process would have been of great benefit to the vendors. It is extremely expensive to implement a statewide system and then discover that edits were not appropriately implemented, data manipulations were not carried out appropriately or reporting capabilities are not accurate. NCHS could have saved with a rather small investment (from a national perspective), the states significant costs and as importantly, the dissatisfaction of their data providers. At this time there a relatively small number of vendors providing electronic vital registration systems to states and yet we have significant problems. With electronic health records, one can assume there will be a much larger number of vendors seeking the business of the many, many thousands of medical providers who have little IT knowledge. Publishing data standards for systems is not enough. Data sharing will only take place if there is confidence in the data specificity and quality of the systems which are passing data to you. Without that confidence, medical providers will be faced with different data systems collecting similar data.

Another approach that is just in the beginning stages for NCHS, is the development of centralized web-based modules which provide unique services such as appropriate use of medical terminology, instituting complex edits, and the provision of tutorials which can be either be embedded or accessed by vendor-based systems. This approach might be a way around the need for certification of entire systems and allow for inexpensive and quick changes to services covered by these centralized web-based modules.