

Minnesota

Project title: Newborn Screening: Program and Data Integration

Organization Responsible: Minnesota Department of Health [MDH]

Service coverage area: State of Minnesota

Annual birth cohort: Approximately 70,000

Project scope and goals

Data and program integration are the project's primary goals. Data integration is being achieved through linkage of the newborn screening database – currently linking dried blood spot and hearing screening databases – with vital statistics, which at present includes birth only. Death records will be added in 2005.

Newborn Screening is receiving regular data loads of vital records, and matching software has been developed, tested, and is being refined. Original plans included direct connection of all newborn screening-identified children to Title V (a children with special health care needs program) for a one-time phone follow-up and assistance to families with referrals to resources and services. Those plans have changed, and integration efforts are now in place to link a specialty care center care coordinator to provide long-term tracking of clinical outcomes for children identified by newborn screening.

The NBS programs have been moved to a Web-based screening application accessible to internal NBS staff. Plans are progressing toward the linking of the newborn screening Oracle database with the Fetal Alcohol Syndrome Registry and the Birth Defects Information System. Initial needs analysis has been initiated for this part of the project. The Newborn Screening Public Health Laboratory has created and maintained the application, which is hosted on a shared MDH server.

Several initiatives from the 2004 Minnesota legislative session are helping this project move its goals and objectives forward to improve linkages for child health information systems. The Governor's proposal included the creation of an electronic medical records system that would allow patient information to be accessed from anywhere and a best practices program to develop standardized treatment based on outcomes information. The legislature agreed that expanding the use of health information technology and electronic health records is a top health priority. The resulting Minnesota e-Health Initiative will be designed to improve health and health care quality, increase patient safety, reduce costs, and improve public health by accelerating the use of electronic health records, personal health records, and other health information technology.

Funding

- MCH block grant
- Newborn Screening Dried Blood Spot fees
- CDC Early Hearing Detection and Intervention grant
- HRSA/MCHB Universal Newborn Hearing Screening grant
- HRSA/MCHB Genetics Program and Data Integration grant

History

A 2001 HRSA/MCHB Genetics Planning grant began the process of child health information systems data and program integration. Small incremental steps assessed the interest of individual programs in linking data systems. The newborn hearing screening and dried blood spot programs were the first programs to integrate their databases and staff in 2002. This integration of personnel has improved the follow-up and tracking of infants and children identified through early identification programs (dried blood spot, hearing, and birth defects), but more efforts are needed to coordinate communications with families and providers to reduce information duplication. In 2004, vital records were linked with newborn screening to ensure that all children are screened. In 2005, death records will be matched with the newborn screening database to avoid contacting families whose infant has died and to assist with future epidemiology and etiology research.

Executive leadership and organizational endorsements

The NBS management team – supervisors, managers, assistance division directors, and division directors from the public health laboratory and Community and Family Health Division – meets bi-monthly to identify strategies for effective and efficient program integration. To maintain this successful collaborative, a Memorandum of Understanding (MOU) with internal partners from the lab and the newly formed Community and Family Health Division is being developed. An MOU has already been fully executed between the Public Health Laboratory and the Center for Health Statistics.

External endorsements

The Newborn Screening Advisory Committee was formally created in MN Statute, July 2003, to provide a mechanism for a streamlined process for adding new tests to the NBS screening panel. Legislative approval is no longer required for each new screening test. The Advisory Committee, consisting of key stakeholders, has several official responsibilities, including “providing advice and recommendations to the commissioner concerning tests and treatments for heritable and congenital disorders found in newborn children.”

Significant challenges

- 1) The integration of child health information systems has involved programs interested in linking, rather than analyzing which key programs are needed to reach specific goals. As a result, the project does not have an overarching knowledge management approach to guide planning so that data collections can best be utilized to optimize the health of children.
- 2) Some child health information systems do not (or by statute/rule cannot) link or match their data with other programs. This results in entering and maintaining the same data on a child in multiple systems, resulting at times in duplication of contacts to consumers and providers.
- 3) Integration in Minnesota lacks a seamless and comprehensive system to ensure that all children and families have access to care.
- 4) Minnesota's public health programs have had difficulty reaching out and being well received by the public regarding the benefits of data sharing and electronic connectivity. Privacy is a hot-button issue in the state.
- 5) Standards need to be developed to allow systems to be interoperable.
- 6) Financial barriers (e.g., lack of adequate funding) have prevented public health from developing integrated systems.

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