Wednesday, January 21, 1:30-3:30PM
Concurrent Breakout Session

Enhancing Birth Defects Surveillance and
Public Health Programs Through Record Linkage Strategies
Moderator: Russell Kirby, Department of Maternal and Child Health School of Public Health, University of Alabama at Birmingham, Birmingham, AL

Overcoming Barriers in Matching Child Health Records
Johanna Steper. New York State Department of Health, Troy, NY

New York State has created a database of de-identified child health records from disparate population-based sources, linked both longitudinally and latitudinally. Since none of the source datasets had been designed with such linkage in mind, we had to resolve a number of problems inherent in the material: different coding schemes for demographic data and geographic data; linkage of datasets with minimal demographic information; poor data quality; incompatible data elements. We have been able to overcome many of these barriers and would like to share our experience with others who are trying to design similar databases.

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Development of a Web-Based Integrated Data Management System:
Virginia Infant Screening and Infant Tracking System (VISITS)

Nancy Ford, Virginia Department of Health, Division of Child and Adolescent Health, Pediatric Screening and Genetic Services, Richmond, VA

Objective: To develop a secure, Web-based integrated data management system that tracks screening results for the following statewide programs and services: (1) Virginia Congenital Anomalies Reporting and Education System (VaCARES—Virginia's birth defects registry), (2) Virginia Early Hearing Detection and Intervention Program, (3) Virginia Newborn Screening Services, and (4) At-Risk for Developmental Delay (Part C of IDEA).

Methods: Using results from the systems analysis of the needs and requirements for all programs and services, a requirements document was completed. Software was developed and modified based on feedback from hospital focus groups and program administrators. User acceptance testing was conducted on the completed modules and modifications were made to the software. Similar processes are planned for the uncompleted modules. The VISITS-Hearing module was rolled out March 2002, and an agency risk assessment was completed May 2002. Following an agency information systems audit review, the VISITS-VaCARES module was rolled out September 2002. A pilot program to test the VISITS-At Risk module began July 2003. The VISITS Newborn Screening module, which involves importing case data from the laboratory information management system (StarLIMS) into VISITS, is under development.

Results: A data integration model was developed that adheres to state and federal best security practices; represents a client in the database only once; generates a unique identifier that can be searched by data elements; grants different levels of access to users for viewing confidential information; allows selected users to enter, modify, and delete records; tracks clients' activities and services through the continuum of care; allows multiple users to view data simultaneously; generates electronic evaluations and plans of care based on selected criteria; produces letters and forms; and provides on-line help.

Conclusions: A statewide integrated data management system can be used to track results for multiple screening and reporting systems. Special challenges included (1) incorporating electronic birth and death certificate data, (2) transferring "old" birth defect data into the new system, (3) underestimating required resources, (4) meeting agency information systems audit requirements, and (5) developing and implementing ongoing quality control processes. Recommendations for successful development include (1) developing an initial flexible business plan; (2) incorporating best security practices throughout the planning phase; (3) keeping end-users informed of expectations and providing adequate training; (4) allowing for continuous modifications to original deliverables; and (5) not underestimating the amount of resources, time, and intra- and inter-agency coordination it takes to develop and implement cutting-edge technologies.

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Child LINK: A Birth Defects Registry as Part of an
Integrated Newborn Data Management System in Maine
Craig A. Mason, Shihfen Tu, and Cecilia Cobo-Lewis - University of Maine, Orono, ME
Patricia Day - Maine Bureau of Health, Division of Family Health, Genetics Program, Augusta, ME

Objective: To create an integrated database system combining information from Maine's Electronic Birth Defects Registry, Universal Newborn Hearing Screen, Metabolic Disorder Database, and Electronic Birth Defects Registry.

Methods: As part of a Maine Bureau of Health/University of Maine collaboration, Child LINK was developed by researchers at the University of Maine's Center of Excellence in Developmental Disabilities. To ensure compliance with HIPAA and state and federal regulation, development occurred in consultation with the Office of the State Attorney General. Both networked and stand-alone versions of key software components were created, with the ability of direct data download by stand-alone software. An initial pilot version of Child LINK was developed in 2002, the Birth Defects Registry went on line in mid-2003, and the Universal Newborn Hearing Screen goes on-line in January 2004. Incorporation of Children with Special Health Needs data is under development.

Results: The Child LINK database is maintained on a secure server operated behind double firewalls with 128-encrypted transmission required for any access. Four general classes of user-specific access are provided, allowing one to enter data for a specific site, see data for a specific site or content area, see data for all sites/content areas, or change data. Information is organized reflecting a *Second-Order Developmental Database* model, allowing authorized users to seamlessly identify and access data from different individuals in fluidly defined, extended families. As part of this model, related data from different sources is integrated and stored so that retrieval of information can be made across all sources based on content, rather than source. All potential time-varying data is maintained and accessible, providing a historic, developmental perspective.

Conclusions: A fully integrated information system can provide a seamless summary of diverse data on birth defects and other early childhood data. This can assist in tracking and planning of services, as well as enhance opportunities for applied, state-based public health surveillance and research. Designing a system from scratch creates a number of challenges, including accessing necessary programmer resources and establishing and authorizing data transfer protocols. Benefits include the flexibility to address unique needs or programmatic interests and to easily expand into new areas that may not operate as modules with existing systems. Key to success is adequate anticipation and planning necessary resources, development of a highly secure protocol based on multiple access levels, and the support and cooperation of programs and agencies.