

Tennessee

Project title: Tennessee Comprehensive Genetics Plan for Integration of Newborn Screening and Health Information Systems

Organization responsible: University of Tennessee Department of Medical Genetics, Graduate School of Medicine, Knoxville

Service coverage area: State of Tennessee

Annual birth cohort: 80,000

Project scope and goals

The statewide genetics plan will integrate the Newborn Genetic Screening (NBS) program and other genetic services into the Information Technology (IT) plan to ensure a more comprehensive public health infrastructure and to coordinate genetic services with all other programs for children with special health care needs (CSHCN).

Funding

Health Resources and Services Administration (HRSA)
Agency for Healthcare Research and Quality (AHRQ)

History

- **2001-03:** HRSA planning grant: Organization of Statewide Genetics Planning Committee (SGPC) and close collaboration between Tennessee Department of Health and Academic Genetic Centers.
- **2003-07:** HRSA Implementation grant, one of five Joint Program Initiatives.
- **2003-04:** The SGPC becomes the Coordinating Committee (SGCC). New members are added. Linkage of databases begins.
- **2004:** Joined HRSA *Connections* community of practice.
- **2004:** AHRQ planning grant awarded.
- **2005:** AHRQ implementation grant proposal submitted.
- **2005:** New collaboration established with Vanderbilt e-health initiative.
- **2005:** Tennessee Child Health Profile (TN-CHP) pilot project begins.

Executive leadership and organizational endorsements

- UT Department of Medical Genetics, Graduate School of Medicine
- Tennessee Department of Health
 - Office of Policy, Planning, and Assessment
 - Office of Information Technology
 - Office of MCH
 - Tennessee State Laboratory
 - Genetics and Newborn Screening
 - Newborn Hearing Screening Program

External endorsements

- Genetic Centers: UT Memphis; Vanderbilt University.
- Sickle Cell Centers: St. Jude Children's Hospital, Memphis; Comprehensive Sickle Cell Center, Meharry Medical College.
- Child Development Centers: Boling Center for Developmental Disabilities, UT Memphis; Center for Child Development, Vanderbilt University.
- TEIS: Tennessee Department of Education.
- Tennessee Division of Mental Retardation Services.
- Council on Developmental Disabilities – Tennessee Department of Mental Health & Developmental Disabilities.
- EPSDT: Bureau of TennCare (state Medicaid)
- Governor's Office on the Coordination of Children's Care
- Consumers
 - Alliance of Genetic Support Groups
 - March of Dimes, Tennessee Chapter
 - Family Voices of Tennessee
 - Tennessee Voices for Children

Significant challenges

Sharing data

- Demonstrate project efficacy
- Communicate with data holders
- Ensure data integrity and security
- Accountability
- Address data silo issues

Linking data

- Matching records between databases
- Identifier issues
- Data duplications

Other issues

- Strategies to maximize non-matches.
- De-identification of records for data analysis.
- Permission forms for providers to view records.
- Matching records with common identifiers.

Contacts

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