

Grant Final Report

Grant ID: 5UC1HS016133

**Improving Quality Care for Children with
Special Needs**

Inclusive Dates: 09/30/05 - 01/31/10

Principal Investigator:

Carmen B. Lozzio, MD, FACMG

Team Members:

John A. Phillips III, MD, FACMG

Tyler Reimschisel, MD

Jewell C. Ward, MD, PhD

Frederick B. Palmer, MD

Brent J Shelton, PhD

Michelle Liao, MS

Billy Hancock

Robert "Bob" Eubanks, BS

Sharon Whipkey, BS

Performing Organization:

University of Tennessee, HSC

Project Officer:

Iris Mabry-Hernandez

Submitted to:

The Agency for Healthcare Research and Quality (AHRQ)

U.S. Department of Health and Human Services

540 Gaither Road

Rockville, MD 20850

www.ahrq.gov

Abstract

Purpose: The purpose of this project is to use Health Information Technology (HIT) to improve the safety and quality of care received by children with special health care needs (CSHCN).

Scope: To improve the safety and quality of health care for CSHCN by providing accurate, comprehensive and integrated health, case management and educational information on CSHCN in a secure web based electronic health record (EHR) called Tennessee Child Health Profile (TN-CHP). To make available to health care providers and parents/legal guardians access to TN-CHP to ensure current information and continuity of care.

Methods: TN-CHP was developed for children with genetic and developmental disorders including those detected by the state Newborn Screening (dry blood spot test) and Newborn Hearing Screening programs. The genetic and developmental specialists of three genetic centers and two centers for developmental disabilities enter the data on diagnosis, treatment and follow-up recommendations into TN-CHP to make it available to the primary care providers in the child's medical home. The partners are the Genetic Centers at the University of Tennessee-Graduate School of Medicine in Knoxville, the Health Sciences Center in Memphis and Vanderbilt School of Medicine and the Child Development Center at Vanderbilt, the UT Boling Center for Developmental Disabilities in Memphis and the department of Information Services at UHS/UT Medical Center in Knoxville.

Results: Major successes include: 1) Development of a comprehensive web based EHR for CSHCN; 2) Participation of major stakeholders representing state departments, academic centers and consumer agencies; 3) Data analysis of outcomes.

Key Words: Web based electronic child health profile; Children with special health needs; Inter-agency cooperation

The authors of this report are responsible for its content. Statements in the report should not be construed as endorsement by the Agency for Healthcare Research and Quality or the U.S. Department of Health and Human Services of a particular drug, device, test, treatment, or other clinical service.

Final Report

Purpose

The purpose of this project is to use Health Information Technology (HIT) to improve the safety and quality of care received by children with special health care needs (CSHCN).

The project's goals:

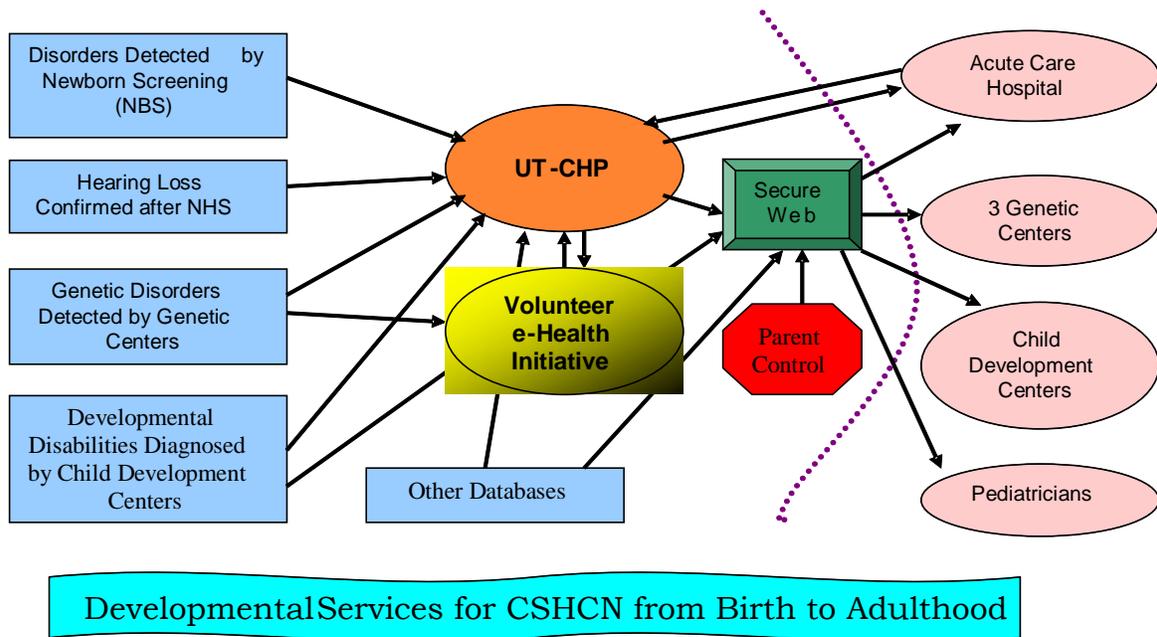
1. Make available to health care providers secure web access to a comprehensive electronic health record of CSHCN (with parental permission) to ensure current information and continuity of care.
2. Improve coordination and quality of care provided to CSHCN in ambulatory settings by the use HIT.
3. Provide accurate, comprehensive health care information for developmental tracking of children from birth to adulthood.

The specific aims for these goals:

- 1.1 The development of an electronic health record called Tennessee Child Health Profile (TN-CHP) linking data from the state's results on newborn screening, and newborn hearing screening with follow-up data from the genetic centers, and additional information from the centers for child development, Figure 1) and to include diagnostic and follow-up data on children with other genetic disorders and developmental disabilities.
- 1.2 Offer to health care providers all relevant health information on a child (with parental permission) from a single secure web source, thus freeing the provider from searching through multiple web sites, electronic records, and manual files to obtain information.
- 2.1 Improve the coordination of services, continuity of care, timelines of follow-up services, and patient tracking to avoid loss of cases that need services and reduce delays in delivering appropriate treatments.
- 2.2 Reduce misinformation on the primary diagnosis of a child when different specialists do not have easy access to primary diagnosis information.
- 2.3 Increase the communication between health care providers and educational systems to improve the quality of life of CSHCN.
- 3.1 Provide continuous updated health information on children for providers to track milestones of development and functioning during infancy, childhood, pre-adolescence, and adolescence.

- 3.2 Provide updated information on diagnosis, treatment and follow-u of CSHCN for providers to improve the quality and safety of services.
- 3.3 Give parents access to their child’s records, and progress made.

Figure 1. Project Data Linkage and Sharing Vision



Scope

Background and Significance

Significant progress has been made in the past four years in the development of standards to assure interoperability for the use of health records. In 2005 HHS secretary Michael Leavitt chartered a public-private organization called "American Health Information Community" (AHIC) to provide input and recommendations to HHS on how to make health records digital and interoperable, and assure that the privacy and security of those records are protected. Four groups contribute information to AHIC: the Certification Commission for HealthCare Information Technology (CCHIT), the Healthcare Information Standards Panel (HITSP), the Health Information Security and Privacy Collaboration (HISPC) and the National Health Information Network (NHIN). HITSP harmonize and integrate standards to meet clinical and business needs. In January of 2008 the Office of the National Coordinator for Health IT (ONC) DHHHS recognized HITSP interoperability specifications and standards for HIT and the important role that HITSP plays in the development of a National Healthcare Information Network (NHIN). Many organizations and members of the IT community participate in HITSP technical and coordinating committees and review and provide recommendations on use cases

from the provider perspective, the consumer perspective and the population perspective. AHIC has been working on different use cases since 2006 and Laboratory Genetics/Genomic Data and Family Medical History were among the priorities for 2008. The Newborn Screening use case was started in 2008 and was a priority in 2009. The other use cases for 2009 included Clinical Encounter Notes, Scheduling, Maternal and Child Health and Medical Home; Co-Morbidity and Registries.(1) All this work will be incorporated in the development of effective electronic health information systems to be used by providers of health care in large health organizations and in ambulatory care.

Adoption of health IT has been very successful in large health systems and has been very limited in ambulatory settings. A recent national survey of physicians has shown that only 4% have a comprehensive system and 13% have a basic system.(2) Literature review and interviews with experts were used to determine the degree of adoption of HIT in seven industrialized nations. The results revealed that four nations (UK, Netherlands Australia and New Zealand) have nearly universal adoption of EHRs among general practitioners (>90%), Germany has 40-80% and US and Canada only 10-30 %.(3) Market factors play an important role on electronic health adoption by physicians and a survey in Florida showed that practice size, years in practice, Medicare payer mix and measures of technology readiness play an important role and financial support will be needed in areas of higher concentration of small practices and Medicare beneficiaries.(4) A survey of office practices in Massachusetts showed that fewer than 1 in 5 medical practices have an EHR and many who have EHRs do not use the functionalities that are necessary to improve health care quality and more than half of the practices that do not have an EHR do not plan for adoption. Inadequate funding is a major barrier for adoption in ambulatory care practices in the USA.(5) The need, benefits and challenges of adoption of EHR in ambulatory care have been well documented in many publications.(6-10) These findings may change with the new Medicare and Medicaid rules for meaningful use of EHRs.(11)

Tennessee has made significant progress towards adoption of HIT in ambulatory settings.(12) In 2006 Governor Phil Bredesen issued an Executive Order and created the Tennessee 's eHealth Advisory Council. To support this council the Department of Finance and Administration established the office of e-Health Initiatives. The e-Health Advisory Council included public and private stakeholders statewide, representing payers, employers, providers, and HIEs. In 2007 the Council working with TN-HIMSS (Tennessee Healthcare Information and Management Systems Society) released results of a survey showing that 83% of physician's practices were connected to broadband but the majority, especially the rural practices had only DSL. In 2009 the State commissioned an extensive study to generate options for further development of HIE in Tennessee. Based on these recommendations the e-Health Advisory Council was replaced by a new not-for-profit organization the Health Information Partnership of Tennessee (HIP TN)

Tennessee has also been a leader in the development of Health Information Exchange (HIE) or Regional Health Information Organizations (RHIOs) The MidSouth eHealth Alliance (MSeHA) is a successful HIE funded by AHRQ and the state of TN in three counties surrounding Memphis.(13) MSeHA started exchanging data from emergency departments in May 2006, hospitalists in four health systems starting accessing the system in September 2007, clinicians at community health clinics started participation in late 2007 and 2008 and is currently extending access to ambulatory practices. A total of 3.9 million encounter records for 1,050,000 unique patients, 2.4 million lab results per month, 35,000 chest X-rays per month and 34,000 ICD-9 codes per month are in the system and greater than 400 users authenticated by secure tokens are accessing these records. Shared Health is a state wide system based on administrative

claims data from TennCare (state Medicaid) members and commercial Blue Cross Blue Shields of TN. This system has data on 1/3 of TN's 6 million citizens with 8,500 users and near 2 million unique patients. CareSpark is an HIE that serves 17 counties in northeast TN and southwest Virginia. Based on significant support from local health care providers, purchasers, technology companies and policymakers is one of only 9 recipients of the National Health Information Network (NHIN) to establish a national model for data exchange and medication management. CareSpark started exchanging demographic data and collecting clinical data in 2008. Innovation Valley Information Network (IVhin) is based in Knoxville and serves 17 counties in East TN. This organization started exchanging data among four major health systems in Knoxville and planned to expand to reach the area physicians that received state's Physicians Connectivity grants. Emerging new HIE are the Davidson County HIE for exchanging information on medication management and ePrescribing among the four major hospital systems in the county. The Middle Tennessee Rural Health Information Network (MTRHIN) in the Upper Cumberland region received a HRSA grant to pilot TN first rural eHealth initiative, the West TN Initiative in the Jackson area is a community driven initiative and the Department of Health e-Prescription Pilot in Wilson county is aimed at implementing ePrescribing for health department patients.

A great deal of the efforts in expanding eHealth in ambulatory care in TN has been aimed to implementing and expanding ePrescribing. However, there is a great need to expand these efforts to provide electronic information on CSHCN.

Context, Settings, and Participants

TN-CHP contains all the results of the NBS and NHS tests that are downloaded from the state laboratory server into our secure servers and are transferred to a secure web database. The TN-CHP electronic version of the state results on NBS and NHS will be available to providers in the same format as the current report mailed or faxed to physicians and has been waived from informed consent by the TN Department of Health IRB because testing is mandated by law and the results are public health data used for clinical purposes only. All the results of diagnostic tests for "out of range"(presumed positives) results are sent by the state NBS Follow-up program to the genetic centers, sickle cell centers and endocrinologists. This information is also in the state database and is downloaded to the TN-CHP servers together with all the laboratory results of NBS tests. Additional data on confirmed diagnosis, treatment and long term follow-up is sent to TN-CHP by the genetic centers and centers for developmental disabilities after the parents have signed the IRB approved informed consent. This data will be made available to providers and parents/legal guardians based on parental consent. An interactive system for physicians and audiologists to report results of hearing evaluations and treatment has been developed and will be available to improve reporting of diagnosis and treatment of hearing loss. We submitted a survey to a list of audiologists that perform follow-up hearing evaluations and received responses indicating that they will be willing to use TN-CHP to report results of hearing tests. We presented the results of this survey to Cindy Wallace, director of Genetics and Newborn Screening and to Jacque Cundall, coordinator for Newborn Hearing Screening at the TN Department of Health in 2008 and they recommended that the audiologists be given access to the hearing data only but not to the laboratory results of the tests performed by the state laboratory. To comply with this request we created a new log in for audiologists that allow them to see and enter follow-up data on hearing while physicians can access both the laboratory results of the

state newborn screening tests and the results of hearing screening as well as confirmatory diagnostic tests and hearing evaluations. An example of how this information can be accessed by audiologists or physicians can be seen on the DEMO version of TN-CHP. In the DEMO an audiologist can log in with the ID "audi1" and password "audi11" and physicians as "doc1" and "doc11". We also improved the page to report results of follow-up evaluations for infants with presumptive positive results on the state newborn screening tests. The new page has additional demographic information and new fields to report results of confirmatory tests performed and linkage to the state reports and relevant literature and resources. Access to NBS and NHS data is available by entering either the unique number given to the initial sample obtained on each child before discharge from the hospital of birth (TDH number), or the mother last and first name, date of birth and place of birth of the child. The educational component is been developed and includes comprehensive information on hearing loss and genetic causes of hearing loss as well as linkage to resources available for providers and consumers. We are improving the descriptions of the disorders screened by the state NBS program and other genetic and developmental disorders. We also continued working with our partners at Vanderbilt and Memphis to improve the developmental disabilities section of TN-CHP.

A strong partnership was developed with six partners representing three separate institutions as statewide collaborations. The six partners represent key providers of services to children with special health care needs in Tennessee. They are also three distinctive entities reporting to separate boards of directors. The UT Developmental and Genetic Center/Department of Medical Genetics, the UT-Memphis Boling Center for Developmental Disabilities, and the UT-Memphis Genetic Center all report to the University of Tennessee Board of Trustees. The UT Medical Center, Knoxville is separate from the University of Tennessee and reports to the Board of Directors of University Health Systems, Inc. The Vanderbilt University Division of Medical Genetics and Center for Child Development report to the Board of Directors of Vanderbilt University School of Medicine in Nashville.

A brief description of the partners:

- 1. The UT Graduate School of Medicine (GSM)** is the Knoxville unit of the University of Tennessee Health Science Center. The Department of Medical Genetics includes the UT Genetic Center that is one of the three comprehensive Genetic/Metabolic Centers in the state. The center provides Clinical Genetic Services including genetic evaluations, in-patient consultations genetic counseling and Newborn Screening Follow-Up. Genetic consultations are available at all area hospitals and are performed by two board certified clinical geneticists. Diagnosis, treatment and follow-up services are provided to infants with metabolic disorders identified through the State Newborn Screening program by a team of clinical geneticist, metabolic nutritionist, genetic counselors and a master level newborn screening coordinator. The Genetic Center has three specialized laboratories: the Cytogenetic Laboratory that performs chromosome analyses and molecular cytogenetic studies with fluorescence "in situ" hybridization techniques (FISH).the Biochemical Genetics Laboratory: that performs assessment of inborn errors of metabolism and Maternal Serum Screening testing and the Molecular Genetics Laboratory: that performs DNA tests for diagnosis and detection of predisposition to a variety of Genetic Disorders.

2. **University Health Systems/UT Medical Center and Memorial Hospital** is the clinical partner to GSM and is committed to staying on the forefront both regionally and nationally. The UHS Department of Information Services, directed by Mr. Douglas Fain, provides systems that support the UHS strategic goals and objectives by enabling coordinated, efficient, and effective access to clinical information throughout the continuum of care. The department manages and assures HIPAA compliant access to electronic health records for the hospital. Our servers are under the firewalls of this department and the server team of IT professionals provides support and maintenance of hardware and software as well as assures the security of the data for this project.
3. **The Division of Medical Genetics (Department of Pediatrics), Vanderbilt University School of Medicine** is directed by John A. Phillips, III, MD, FACMG, and is one of three Genetic/Metabolic Centers in the partnership. General genetic clinics are available at Vanderbilt University Medical Center (VUMC) and in outreach clinics at public health departments in Middle Tennessee. Enzyme replacement therapy is provided for a variety of metabolic conditions. The center has the following genetic laboratory services: Clinical Biochemistry Laboratory with the technical testing based in the Pathology department and the interpretation of the results done by the Medical Genetics faculty. The Molecular Diagnostics Laboratory, directed by Dr. Cindy Vnencak-Jones offers a variety of DNA analysis tests. Research currently being conducted in the Division of Medical Genetics (Department of Pediatrics) involves collaborators within the Vanderbilt community, the United States (academic and private industry) and the international community. Areas of focus include causes and treatment of collagen disorders and the molecular genetics of a variety of genetic disorders.
4. **University of Tennessee, Health Science Center in Memphis–Division of Medical Genetics at the Department of Pediatrics; and the Division of Reproductive Genetics at the Department of Obstetrics-Gynecology.** The Division of Medical Genetics (Genetic Center) is directed by Jewell C. Ward, MD, PhD, FACMG is one of three state comprehensive Genetic/Metabolic Centers. The division has three full-time ABMG Certified Clinical Geneticists that provide clinical genetic services and in-hospital consults. The division has affiliation with the Department of OB/GYN; ABMG Certified Reproductive Clinical Geneticist. This Center, in conjunction with the U.T. Boling Center for Developmental Disabilities, has provided follow-up diagnostic and nutritional treatment services in W. Tennessee for presumed positives of inborn errors of metabolism detected by the state NBS program. Genetic associates include an ABMG Certified Genetic Counselor, and two Genetic Nurses. An outreach clinic is located in Jackson. This Center has the following genetic laboratories: Clinical Cytogenetic and Molecular Cytogenetic Laboratory, the Inborn Errors of Metabolism Laboratory for on-site monitoring of PKU patients in W. Tennessee, N. Mississippi and E. Arkansas. This center continues to forge linkages with non-pediatric departments on campus and with the basic science molecular resource centers.
5. **The Center for Child Development, and the Division of Developmental Medicine and Cognition, Department of Pediatrics, Vanderbilt University School of Medicine.** The Center for Child Development in the Division of Developmental Medicine and Cognition at Vanderbilt provides interdisciplinary screening, medical evaluation and treatment, and psychological testing and therapy for children and adolescents with a wide

variety of developmental concerns, including developmental delay, cognitive impairment and intellectual disabilities, autism spectrum disorders, spasticity, and ADHD and other behavioral problems. The Center also offers specialized clinics for Down syndrome, Fragile X, and the genetics of developmental disabilities. Behavior training for families of children with behavior concerns is available in clinic and in homes. Clinical and outreach services are provided by a diverse team of experts including developmental and behavioral pediatricians, general pediatricians, psychologists, a neurogeneticist, nurse practitioners, nurses, education consultants, behavior specialists, social workers and students in the healthcare professions. The Center is the principal diagnostic center for developmental disabilities in Middle Tennessee, southern Kentucky, and northern Alabama. Faculty and staff in the Center also participate in a multitude of research projects, including autism spectrum disorders (Autism Treatment Network), cognitive impact of urea cycle defects, medication intervention for individuals with Fragile X, and the development and implementation of a State of Tennessee early intervention database.

- 6. The UT Boling Center for Developmental Disabilities.** The Boling Center for Developmental Disabilities (BCDD) is part of the University of Tennessee Health Science Center's College of Medicine in Memphis, and is an interdisciplinary program whose mission is to improve the lives of individuals with developmental disabilities and their families through research, training, service, technical assistance, and prevention activities. The BCDD's interdisciplinary clinical programs include participation from a broad range of health professionals including pediatricians, nutritionists, psychologists, psychiatrists, speech and language pathologists, social workers and others. In collaboration with Pediatric Genetics, the BCDD sponsors the Inborn Errors of Metabolism Program for West Tennessee that provides follow-up care to children with metabolic disorders. The BCDD serves children with a wide array of developmental disabilities and special health care needs through clinical programs at the Center and in outreach programs. This Center is part of the University of Tennessee Health Science Center's College of Medicine in Memphis. The BCDD has core support as Tennessee's Center of Excellence in Developmental Disabilities, Education, Service and Research. It also receives support from the Maternal and Child Health Bureau for Leadership Education in Neurodevelopmental and Related Disorders.

Incidence, Prevalence

Approximately 13 percent of all American children have a special health care need.(CSHCN; 14-16) Tennessee has about 90,000 births per year, thus more than 10,000 children are born each year in Tennessee that may be diagnosed with a disability during their childhood. Many CSHCN are disproportionately poor, socially disadvantaged, and face significant barriers to health care. Nearly 18% have an unmet need for specific care services (14, 17), 11% had no personal care provider (1, 8), and nearly 22% encountered difficulty receiving referrals for specialty care.(14,17) Most of CSHCN who lived in the South or West had increased limitations, low socioeconomic status and they were significantly more likely to have experienced delayed or forgone care.(3) Financial problems and time conflicts were among the major factors associated with delayed or forgone health care for CSHCN.(16)

Methods

Design

The Tennessee Child Health Profile (TN-CHP) is a web based electronic health record designed to offer comprehensive information on each child using data from state programs and follow-up services in support of the medical home. The data on newborn screening (NBS), newborn hearing screening (NHS) and short term follow-up is included in the Newborn Screening Data section. The long term follow up, medical treatment and developmental information is reported in the Child Data section. An educational component is accessible to all providers, case managers and families while the confidential information on both the Newborn Screening and Child Data sections is secure and accessible only to those authorized to access this information.

Data sources/ data collection

The results of the state mandated newborn screening (NBS) also known as "dried bloodspot screening" performed by the State Laboratory and the newborn hearing screening (NHS).performed at the hospital of birth and sent to the state NHS program was downloaded from the state servers into our secure servers TN-CHP has three databases housed in Oracle 10G servers (one for the DEMO, one for Production and one for testing and development of the system) and two Web servers (one for the DEMO web version and the other for the Production web confidential records). All the servers are under the firewall of the network of the University Health Systems, Inc (UHS)/UT Hospital Department of Information Technology and have SSL license to protect the confidential information. The software used to develop the program is C#. TN-CHP received all the results of the laboratory tests performed by the state lab for NBS and all results of NHS by VPN download from the state Oracle server to our Oracle 10 g servers. The data on confirmatory diagnosis, treatment and follow-up for NBS and NHS was entered by the staff of the Genetic Centers and data on cases with other genetic diagnosis and/or developmental disabilities was entered by the staff at the genetic and developmental centers that have administrative access to TN-CHP production database.

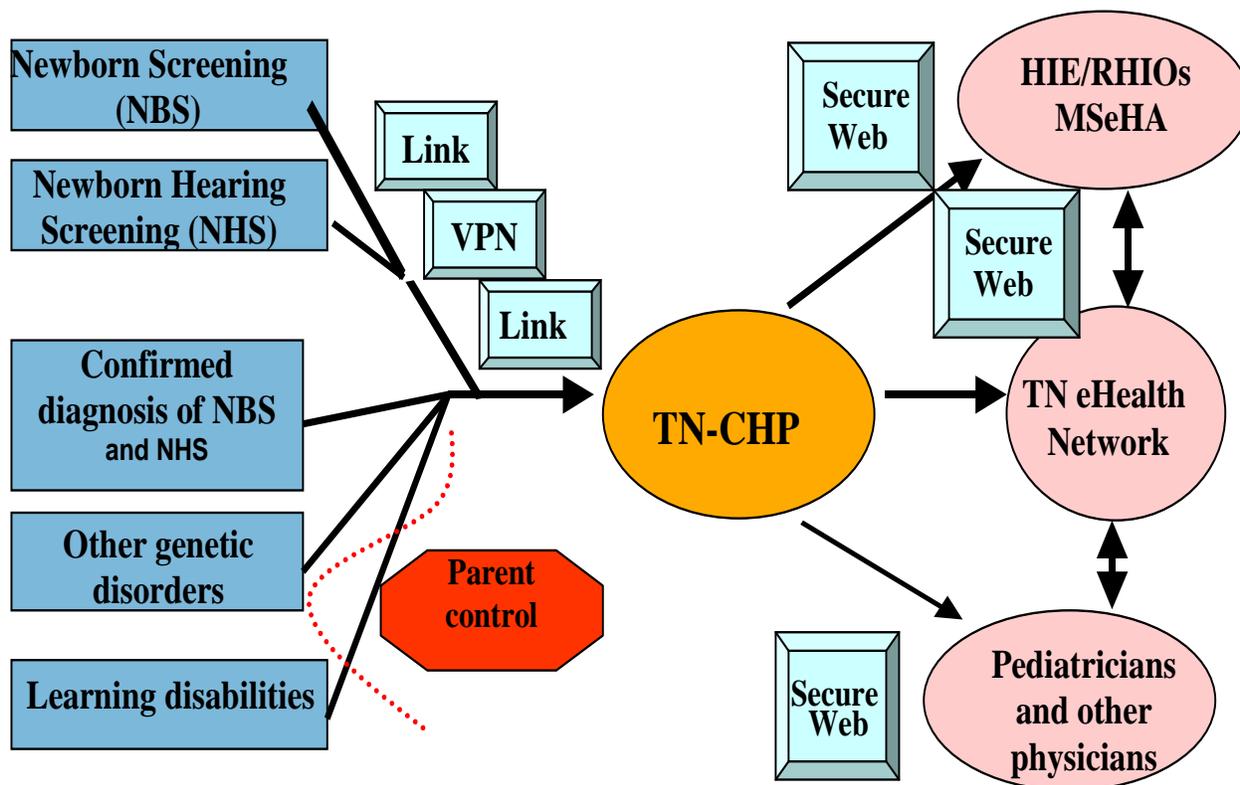
Interventions

The TN-CHP electronic version of the state results on NBS and NHS is available in the same format as the current report mailed or faxed to physicians. An interactive system for physicians and audiologists to report results of hearing evaluations and treatment has been developed and will be available to improve reporting of diagnosis and treatment of hearing loss. Based on recommendations of the TN Department of Health the audiologists are given access to the hearing data only but not to the laboratory results of the tests performed by the state laboratory and we have created a log in for audiologists that allows them to see and enter follow-up data on hearing while physicians can access both the laboratory results and the results of hearing screening and confirmatory diagnostic tests and hearing evaluations.

Access to the data by pediatricians and other physicians was proposed to be done thru the TN eHealth Network and HIE programs such as MSeHA. A grant proposal was submitted to the state eHealth Council and was included in the state strategic plan. Unfortunately, the state is facing a significant budget deficit and the federal funds received from the Stimulus Recovery Plan (ARRA) were significantly lower than originally expected and our proposal could not be funded.

The TN-CHP broad scheme of receiving data and making the data available to physicians was the following:

Figure 2. TN-CHP broad scheme of receiving data and making the data available to physicians



Measures

The following outcomes were measured:

1. Percentage of presumptive positive results from the state Newborn Screening (NBS) program with confirmed diagnosis.
2. Length of time between sample collection, results of NBS and confirmed diagnosis.
3. Percentage of infants who failed the initial Newborn Hearing Screening (NHS) and have a confirmed hearing loss.
4. Percentage of children evaluated at the Genetic and Child Development Centers who have confirmed diagnosis and receive coordinated comprehensive care.

5. Tracking of follow-up services by primary diagnosis and history of services received.

Limitations

The project had planned to utilize the HIT infrastructure developed by the state to give access to TN-CHP to physicians. In 2008 the TN eHealth Council established the Tennessee eHealth Exchange Zone by opening the statewide broadband network (the network that the state uses for its business) for the use by health care providers for the purpose of treatment and other allowable uses by HIPPA. The Exchange Zone was available in all 95 counties of the state and was based on the carved out of a specific "channel" of the NetTN state network with high security protections and HIPPA compliant authentication. Grants were awarded by the state to doctors for e-prescribing and 315 sites and 1350 providers received these state grants by February 2009. Also TN was awarded \$7.998 million by FCC to connect 440 sites and 980 providers to be implemented by March 2009 and HRSA awarded a grant to 5 sites and 20 providers in Middle TN rural counties to connect them by February 2009. These grants were awarded to 760 sites and 2350 providers were connected to the Exchange Zone. Medicaid Transforming grants also targeted 14 of TN's most rural counties to connect physicians to broadband to implement ePrescribing. A grant proposal was submitted to the state eHealth Council and was included in the state strategic plan. Unfortunately, the state is facing a significant budget deficit and the federal funds received from the Stimulus Recovery Plan (ARRA) were significantly lower than originally expected and our proposal could not be funded.

Results

Principal findings

Development of an integrated EHR (TN-CHP) for CSHCN. One of the major accomplishments of this project is the development of the Tennessee Child Health Profile (TN-CHP) a web based electronic health record designed to offer comprehensive information on CSHCN diagnosed as the result of the state Newborn Screening and Newborn Hearing programs and those with a genetic or developmental disorder diagnosed at three genetic centers and two centers for developmental disabilities. The Newborn Screening section contains the data on results of the newborn screening tests performed by the State Laboratory and of newborn hearing screenings performed in the hospitals of birth as well as data on short term follow-up evaluations and results of tests performed to confirm the diagnosis. The TN-CHP electronic version of the state results on NBS and NHS is available in the same format as the current report mailed or faxed to physicians. Additional data on confirmed diagnosis, treatment, developmental information and long term follow-up sent to TN-CHP by the genetic centers and centers for developmental disorders is included in the Child Data section of TN-CHP This section also has information on diagnosis, treatment, developmental evaluations and link to resources for children with other genetic and developmental disorders diagnosed at the three genetic and two developmental centers that are partners in this project. An educational component includes comprehensive information on hearing loss and genetic causes of hearing loss, disorders

diagnosed by NBS and other genetic conditions and developmental disabilities as well as linkage to resources available for providers and consumers. The educational section is accessible to all providers, case managers and families while the confidential information on both the Newborn Screening and Child Data sections are secure and can only be viewed by to the professionals authorized to access this information. The parents/legal guardians can view the data on their own child and can make comments but cannot change the information included in their child's record. A view of the homepage:

Figure 3. Tennessee Child Health Profile (TN-CHP) home page



Examples of the educational information provided:

Figure 4. Sample Web page: Newborn screening

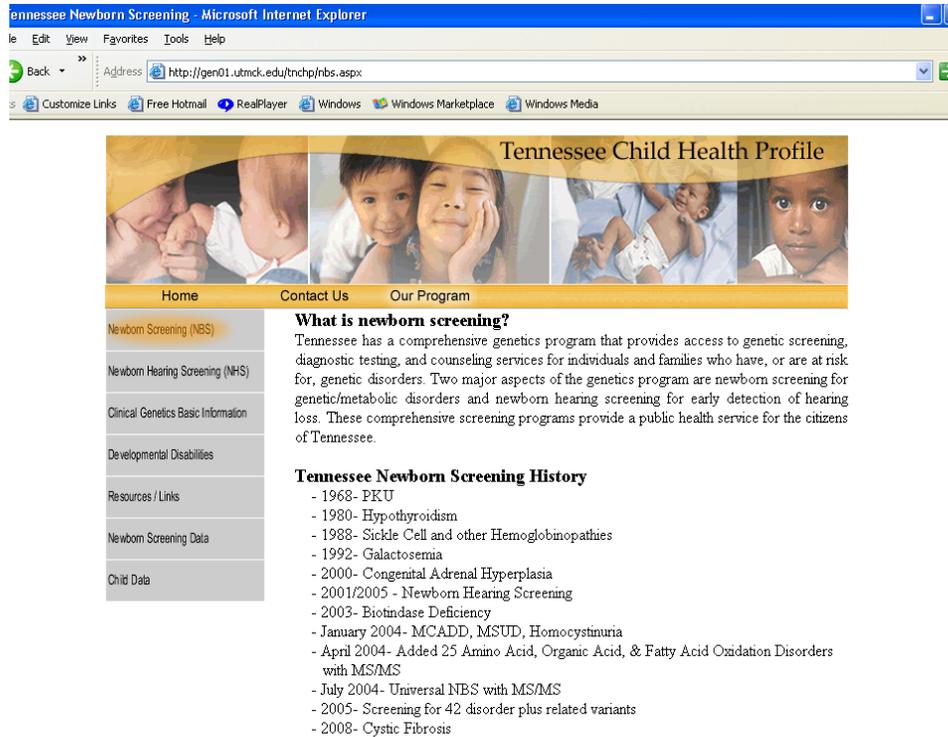


Figure 5. Sample Web page: Why screening is important?

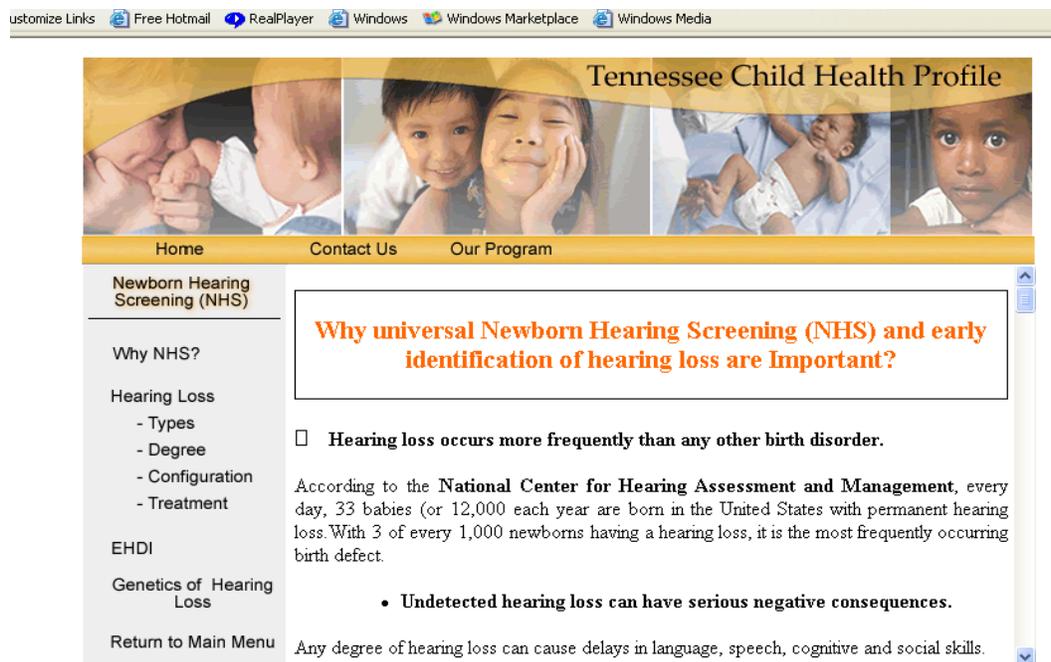
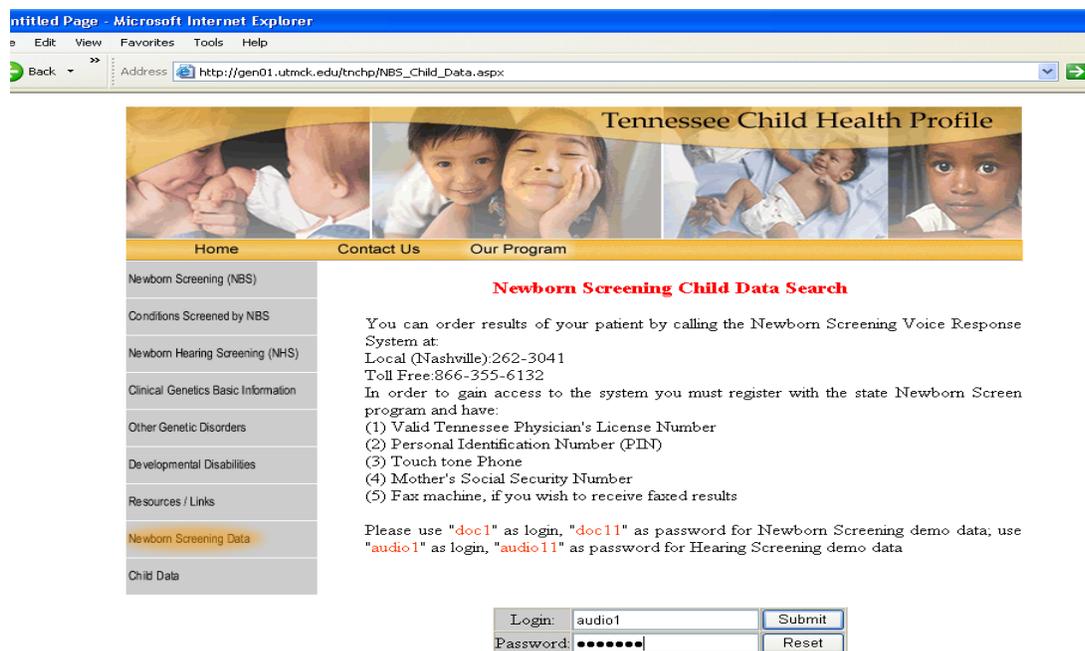


Figure 6. Sample Web page: Genetics of hearing Loss



Access to NBS and NHS requires a secure ID and password. An example from the DEMO version of TN-CHP:

Figure 7. Example of the secure login page at the TN-CHP Web site



The NBS and NHS data can be accessed by entering either the unique number given to the initial sample obtained on each child before discharge from the hospital of birth (TDH number), or the mother last and first name, date of birth and place of birth of the child. The following is an example from TN-CHP DEMO.

Figure 8. Data search at TN-CHP Web site

Tennessee Child Health Profile (TN-CHP)

Newborn Screening Data Search

Please use TDH "2006xxxxx15" or "2006xxxxx63" for demo data

TDH Number:	<input type="text"/>
Or:	
Mother L_Name:*	Sanderson
Mother F_Name:*	Robin
DOB: (mm/dd/yyyy):*	12/21/2006
Hospital of Birth:	Fort Sanders Regi

Access to Child Data that contains medical, developmental long term follow-up requires parental consent and the provider physician can only access data on his/her patients who have signed the IRB approved informed consent. This is an example of a list of patients shown in the TN-CHP DEMO.

Figure 9. Example of a list of patients at the TN-CHP Web site

LNAME	FNAME	MNAME	DOB	COUNTY	TDH_Number	Mother_LNAME	Mother_FNAME	Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Abbott	John		01/16/2004	Union				Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Borges	Sarah		01/29/2004	Hamilton				Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Jones	Boy		05/22/2005	Hamblen				Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Lopez	Gui		07/16/2002	Sevier				Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
MASSON	GIRL		08/23/2006		2006xxxxx15			Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Masson	Jill		08/23/2006	Greene		Masson	Betty	Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Peters	John	E	07/26/0004	Knox				Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
SANDERSON	GIRL		12/21/2006					Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Smith	Gui		07/16/2000	Jefferson	2006xxxxx63			Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data
Vider	Gui		09/27/2003	Hamilton	2007xxxxx04			Child Info	Diagnostic Evaluation	Developmental Disabilities	Newborn Screening Data

Significant progress was made in the programming of this web site. The educational component has updated linkage to literature and resources, the sections on Newborn Screening and Child Data were designed to allow the view of the complete reports as attached PDF files. These sections also have complete demographic information, reports of clinical evaluations and results of laboratory studies and other diagnostic tests. The Child Data includes a section on Developmental Disabilities with information on psychological and educational evaluations, TEIS referrals, and behavioral management. This section was developed in collaboration with the Memphis IT staff that designed the website for the Boling Center for Developmental Disabilities.

Participation of major stakeholders. Active participation and collaboration of the six partners and of other major stakeholders representing various state departments, academic programs and consumer organizations has been a strong aspect of this project. The purpose of this collaboration is to improve the coordination of services, continuity of care, timeliness of follow-up services, and patient tracking to avoid loss of cases that need services and reduce delays in delivering appropriate treatments for CSHCN.

The partners of this project have a very active system of collaboration to assure timely confirmation of the diagnosis and initiation of treatment of conditions detected by the newborn screening and newborn hearing screening programs of the state of TN. and development of a system of reporting of the appropriate treatment and follow-up recommendations for the care of these children.

The Statewide Genetics Coordinating Committee (SGCC) met twice a year in May and November during the whole period of this grant (2005-2010) and conference calls of the members of the subcommittees were scheduled frequently. The SGCC has 35 members representing five state departments, consumer organizations, and academic institutions and at least twenty members were present at each meeting. At each meeting, the director/PI for the

AHRQ funded project presented an update of the progress made during that period. Invited speakers provided updates on other state programs that collaborate with this project. These speakers were the following: the director of the state eHealth Initiatives, the Director, the Program Manager and the Technical Project Manager for Regional Informatics Programs, Vanderbilt Center for Better Health, the director of Genetics and Newborn Screening, the Coordinator for Hearing Screening and the director of the State Laboratory of the TN Department of Health, the director and the Contract Manager for the Office of Early Childhood, TN Department of Education and the director of Family Voices of TN.

Outcomes

The outcome measures are aimed at improving quality of care for infants and children with special health care needs (CSHCN) especially those diagnosed as the result of the state NBS and NHS programs. The number of confirmed diagnosis due to follow-up testing of the results with "out of range " values in NBS is important to measure the benefits of early detection of conditions that can lead to death or severe disability if the treatment is not started soon after birth. The measure of the delays between birth, collection of the sample and reporting of results is essential to determine the efficiency and effectiveness of the system develop to follow abnormal results and to be able to confirm the diagnosis and start the treatment to prevent abnormal outcomes. The number of cases with confirmed hearing loss among infants that failed the initial hearing screening is important because early intervention should be started early to improve outcomes.

Confirmatory diagnosis and follow-up data on Newborn Screening (NBS) and Newborn Hearing Screening (NHS)

The results of NBS program in Tennessee. In 2005 a total of 3346 "out of range" presumed positive results were reported and 176 had a confirmed diagnosis. In 2006, the presumed positive were 3386 and 180 cases had a confirmed diagnosis. In 2007, 3041 were presumed positives and 164 were confirmed as affected by a specific condition. In 2008, the presumed positives were 2096 and 200 were confirmed as affected by the screened condition. In addition, 2804 infants in 2005, 2491 in 2006, 2531 in 2007, and 2691 in 2008 had a presumed Hemoglobin trait. From January to September of 2009, 2247 presumed positives, 119 confirmed cases and 2015 traits were found. All confirmed cases were treated and followed by the three comprehensive genetic centers that are partners of this project.

The results of the NHS program in Tennessee. In 2008 a total of 90,887 infants were born and 85,380 were screened: 81,554 passed and 3,563 failed, follow-up audiological evaluation identified 77 cases with hearing loss, 2,357 had normal hearing, 125 had pending results and 1,004 needs follow-up. Tennessee is meeting the EDHI goals as follows: in calendar year 2008 93.9% of all newborn were screened and 98% were screened before 1 month. The total completed follow-up was 68.9% and 98.3% were followed before 3 months. The total number enrolled in early intervention was only 21% with a state goal of 50%. In the first six months of 2009, 97.1% of the infants born in the state were screened before 1 month and 83% had completed follow-ups before 3 months. The enrollment in early intervention was still at 14%.

Statistical analysis of outcome measures for follow-up of Newborn Screening (NBS).

This work was conducted by our consultant biostatistician. The outcome measures analyzed are important to assure a timely and efficient system of processing the samples, analyzing the results and assuring quality care for newborn with a presumed disorder detectable by NBS. This is essential to improve the quality of care provided to infants with conditions that can cause severe disability or death if they are not diagnosed and treated soon after birth. The lag times based on birth weight are important because many premature babies are in intensive care and screening may be delayed due to the treatment of other conditions that are critical for survival.

The lag times from date of birth to date of collection of the first sample and to date of report of results for 486 infants reported to the Comprehensive Genetic Center in East Tennessee as presumed positives for metabolic disorders were analyzed. The following results were obtained for infants born in 2007 and the first six months of 2008 when compared by birth weight.

Lag from DOB to first collect:

1. There is a statistically significant difference in mean lag time of 1.65 days from DOB to first collect between the low birth weight babies (< 1500 g) and those weighing at or more than 2500 g ($p < 0.0001$).
2. There is also a statistically significant difference in mean lag time of 1.35 days from DOB to first collect between the low birth weight babies (< 1500 g) and those weighing between 1500 g and 2500 g ($p = 0.0014$).

Lag from DOB to first report:

1. Low birth weight babies (< 1500 g) experience a mean lag time from DOB to First Report that is nearly 5.0 days longer than babies with weights from 1500-2500 g ($p = 0.0192$) and over 9.0 days longer than babies with weights ≥ 2500 g ($p < 0.0001$).
2. Babies weighing 1500 to 2500 g at birth experience a mean lag time from DOB to First Report that is slightly over 4.0 days longer compared to babies with birth weights at or more than 2500 g ($p = 0.0178$).

Lag between first collect and first report:

1. Low birth weight babies (<1500g) experience a mean lag time from First collect to First Report that is nearly 5.0 days longer than babies with weights from 1500-2500 g ($p = 0.0272$) and 7.3 days longer than babies with weights ≥ 2500 g ($p < 0.0001$).
2. Babies weighing 1500 to 2500 g at birth experience a mean lag time from First collect to First Report that is 4.6 days longer compared to babies with birth weights at or more than 2500g but was only borderline significance ($p = 0.1097$).

The lag times from date of birth (DOB) to first, second and third collects were analyzed by birth weights for the years 2003 to 2008 and the results for 2008 are as follows:

Table 1. Lag times in Tennessee Newborn Screening Data from Neometrics in 2008

	Lag from DOB to first collect	Lag from DOB to second collect	Lag from DOB to third collect
Birthweight < 1500 g (N=2,560)	N=2538 Mean=3.2 days Median=2.0 days Range=(0,377) days	N=772 Mean=17.1 days Median=14 days Range=(0,116) days	N=179 Mean=29.5 days Median=27.0 days Range=(7,125) days
Birthweight 1500- 2500 g (N=8,371)	N=8351 Mean=3.0 days Median=2.0 days Range=(0,368) days	N=1304 Mean=14.4 days Median=11.0 days Range=(0,94) days	N=242 Mean=30.0 days Median=23.0 days Range=(6,175) days
Birthweight >=2500 g (N=78,900)	N=78768 Mean=1.9 days Median=2.0 days Range=(0,371) days	N=4495 Mean=21.8 days Median=14.0 days Range=(0, 368) days	N=702 Mean=44.6 days Median=29.0 days Range=(0,347) days

Discussion

This project demonstrated the benefits of developing a web based electronic health record to summarize medical information on diagnosis, treatment and educational resources for infants and children with complex disorders that require coordinated care by many different specialists. Many specialists and agencies are involved in the care of CSHCN The parents often take copies of multiple reports when they take their children to each one of these visits and case managers help them coordinate services. However, even when each physician uses one of the standard commercially available EHR they do not address the special needs, results of diagnostic tests and recommendations from other physicians treating the child and from other agencies and providers of care for these children. We have been working on the development of a secure web based electronic health record called Tennessee Child Health Profile (TNCHP) that provides access to public health data such as results of newborn screening (NBS) and newborn hearing screening (NHS) using the Newborn Screening Data section of TN-CHP and additional medical, genetic, developmental and educational information on a child (with parental permission) using the Child Data section of TN-CHP. It is expected that this information on each child with confirmed diagnosis and linkage to resources will save time for the primary care providers that will not need to search multiple web sites, electronic records, and manual files to obtain information on the primary diagnosis of the child.

Conclusions

A comprehensive web based electronic health record called Tennessee Child Health Profile (TN-CHP) was developed to summarize the most relevant information on diagnosis, treatment and follow-up of infants with conditions detected by the state NBS program and for children with genetic and developmental disorders diagnosed at the Genetic and Developmental Centers in the state. An educational component was included in this website to help physicians and other providers of health care obtain quick access to up to date information and resources available for each condition and reduce the time they need to spend accessing relevant information.

A network of partners and stakeholders was organized to improve the coordination of services, continuity of care, timeliness of follow-up services, and patient tracking to avoid loss of cases that need services and reduce delays in delivering appropriate treatments for CSHCN.

Significance

The main benefit of this project is the development of a HIT system to promote improvement of ambulatory healthcare services and quality of care to CSHCN through a synergistic relationship of academic genetic and child development specialists, state programs, physicians and other health care providers.

References

1. HITSP: <http://www.hitsp.org>
2. DesRoches CM, Campbell EG, Donelan K, et al. Electronic Health Records in Ambulatory Care—A National Survey of Physicians *N Engl J Med* 2008;359(1) :50-60
3. Jha AK, Doolan D, Grandt D, et al The use of health information technology in seven nations *Int J Med Inform.*2008;779(120) :848-54
4. Abdolrasulnia M, Menachemi N, Shewchuck RM, et al. Market effects on electronic health record adoption by physicians *Health Care Manage Rev* 2008; 33(3): 243-52
5. Simon SR, McCarthy ML, Kaushal R, et al Electronic health records: which practices have them, and how are clinicians using them? *J Eval Clin Pract* 2008;14(1):43-47
6. Bates DW. Physicians and ambulatory electronic health records. *Health Affairs* 2005 24 (5)1180-1189,
7. Bodenheimer, T. Coordinating care—Perilous journey through the health care system. *N Engl. J Med.*2008, 358 (10)1064-1071
8. Hornberger, J Electronic Health Records: A Guide for Clinicians and Administrators *JAMA* 2009 301:110
9. Godstein, M.M., Blumenthal, D. Building an information technology infrastructure *J Law Med Ethics* 2008 36:709-715,
10. Armstrong, M.J., Booth, C, Spinello, I.M.et al.Electronic health records in ambulatory care *N Eng J Med* 2008;359:848-1849
11. Medicare and Medicaid Programs; Electronic Health Record Incentive Program; Proposed Rule (CMS-0033-P) *Federal Register* / Vol. 75, No. 8 / Wednesday, January 13, 2010
12. State of Tennessee-The Governor's eHealth Council: <http://www.tennesseeanyttime.org/ehealth/>
13. MidSouth eHealth Alliance: <http://www.midsoutheha.org/>
14. Van Dyck, PC, Kogan, MD, McPherson, MG, et al.,Prevalence and characteristics of children with special health care needs. *Archives of Pediatric and Adolescent Medicine*, 2004;158:884-890.
15. U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *Chart book on the National Survey of Children with Special Health Care Needs*. Rockville, MD: U.S. Department of Health and Human Services; 2004.
16. Huang, Z.J., Kogan, M.D., Yu, S.M, Strickland, B. Delayed or forgone care among children with special health care needs: An analysis of the 2001 National Survey of Children with Special Health Care Needs. *Ambulatory Pediatrics*, 2005; 5 (1), 60-67.
17. Newacheck, P.W., Hughes, D.C., Hung, Y.-Y. et al. The unmet health needs of America's children. *Pediatrics* 2000; 105 (4): 989-997.

List of Publications and Products

Publications and Presentations

Hollar, D.W., Copeland, M.A., Lozzio, C. et al Linking Public Health Databases: Developing Partnerships, Infrastructure, and Testing In Association of Maternal and Child Health, 2005 February 19-23 Washington, DC

Lozzio, CB, Hollar, DW, and Eubanks, R. Electronic Child Health Profile for Children with Special Needs In AHRQ-2005 Annual Patient Safety and Health Information Technology Conference, Session on Health IT and Pediatrics, 2005, June 8, Washington DC

Lozzio, C. Tennessee Newborn Screening. In SERGG Regional Forum Meeting- 2005, September 29-30. Birmingham, Alabama.

Lozzio, C Tennessee Genetics Child Health Profile. In SERGG Regional Annual Meeting- 2005, September 29-30. Birmingham, Alabama,

Hollar, D.W., Lozzio, C., Eubanks, R.L. et al. The key elements in partnership and infrastructure development for electronic child health profiles: A description of two parallel, complementary projects. The 133rd American Public Health Association annual meeting, 2005, December 9-14 Philadelphia

Lozzio, C Improving Quality Care for Children with Special Needs In Connecting Kids through Child Health Information Systems. An Affiliate Meeting to the 5th Annual Forum for Improving Children's Health Care. 2006 March 15-16. Orlando, Florida

Lozzio, C, Lamberth, M, Hollar, D. et al. Integration of Newborn Screening and Health Information Systems. ACMG Annual Clinical Genetics Meeting- 2005, March 23-26. San Diego, CA,

Lozzio, C, Eubanks, R, Lemak, R Tennessee Hit Program to Improve Quality Care for Children with Special Health Care Needs, AHRQ-2006 Annual Patient

Safety and Health Information Technology Conference, 2006, June 4-6 Washington, DC

Lozzio, C. The Tennessee Model using Health Information Technology for Follow-up of Newborn Screening Southeastern Regional Genetics Group, Inc (SERGG) annual meeting 2007 July 26 - 28, New Orleans

Lozzio, C, Improving Quality of Care for Children through Health IT-the Tennessee Project for Children with Special Health Care Needs AHRQ Annual Meeting 2007, September 26 Washington DC

Lozzio, C. Child Health Profile for children with Special Health Care Needs Annual Meeting of the American Academy of Pediatrics Council on Clinical Information Technology 2007, October 26., San Francisco

Lozzio, C. Integrating Newborn Screening and Child Health Systems in Tennessee at The Convergence of Genomic Medicine and Electronic Health Records, American College of Medical Genetics, 2008, February 20, Washington DC

Lozzio, C, Cundall, J., Nicodemus, B. et al. TN-CHP: Web model to improve follow-up of hearing screening poster presentation at Early Hearing Detection and Intervention (EHDI) national meeting 2008, February 24 - 26, New Orleans,

Lozzio, C, Liao M, Hancock, B Tennessee Child Health Profile (TN-CHP) Statewide Genetics Coordinating Committee meeting, November 13, Nashville TN, 2009.

Lozzio, C, Health Information Technology (HIT), Electronic Health Record (EHR) and Genetic Services, GMS Research Seminar, 2010 April 27, Knoxville TN

Lozzio, C, Liao M, Hancock, B Tennessee Child Health Profile (TN-CHP) for Children with Special Health Care Needs, manuscript in preparation.

Products

Brochures on Tennessee Child Health Profile (TN-CHP) for professionals and an Information Guide for Parent