



Heartland Genetics Services Collaborative:  
Annual Report  
2012-2013  
November 2013

Interdisciplinary Center for Program Evaluation

Collaborate

Evaluate

Improve

## PROGRAM DESCRIPTION

The Heartland Genetics Services Collaborative (formerly the Heartland Genetics and Newborn Screening (NBS) Collaborative) is a network of representatives (parents, patients, clinicians, researchers, industry representatives, laboratorians, and public officials) from eight (8) states. This eight-year-old Collaborative actively engages with its partners at a regional and national level to increase access to and improve quality of genetic and NBS services in the region and, at the same time, contribute to projects of national significance. This work is completed under the leadership of the Heartland Regional Coordinating Center (HRCC) with planning and direction supported by the Heartland Advisory Board and three work groups [e.g., Newborn Screening (NBS), Clinical Services, and Advocacy] and through a grant from the Health Resources and Services Administration (HRSA). The Heartland Collaborative implemented strategies related to five primary HRSA priorities for this funding cycle:

**HRSA Priority 1:** Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care.

**HRSA Priority 3:** Expand the pool of the genetic service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties and educators.

**HRSA Priority 4:** Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services.

**HRSA Priority 8:** Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.

**HRSA Priority 10:** Any other program priority that addresses the needs of the region and the program goals.

## Heartland Collaborative Evaluation Findings

The purpose of this report is to provide a summary of the evaluation findings regarding the Heartland Collaborative's implementation of program activities, its success in accomplishing program outcomes and performance on HRSA outcome performance measures. A multi-method approach, including qualitative and quantitative methodologies, was used to help inform the continuous improvement process. Built into the evaluation process was the ongoing review of evaluation data based on the Heartland Collaborative's five HRSA priority areas to inform program improvement through reflection and action planning. The results of the evaluation are summarized in the following:

**HRSA Priority 1:** Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care.

USE THE INDIVIDUALIZED HEALTH PLAN (IHP) TO ENHANCE COORDINATED, CONTINUOUS AND FAMILY-CENTERED CARE FOR CHILDREN WITH GENETIC CONDITIONS IN THE SCHOOL SETTING.

**Key Finding:** The Heartland Collaborative IHP Learning Community (LC) was rated positively, creating a trusting environment among team members. The IHP LC members view their work as potentially having a concrete impact on the quality of health care in educational settings for children and youth with special health care needs.

**Key Finding:** Few IHP team members rated their implementation process as effective and identified several areas for improvement (baseline data).

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### Supporting Evidence

#### IHP Learning Community Project

The goal of the IHP Learning Collaborative (LC) was to demonstrate that effective policies and procedures could improve the IHP process in schools and support school nurses in providing quality care to children and youth with special health care needs (SHCN) and/or genetic conditions. The Learning Collaborative will support state teams to develop high quality IHP

practices, policies and resources that will be implemented to assess impact on student outcomes.

Learning Collaborative participants from the eight states (Kansas, Iowa, Nebraska, Missouri, Arkansas, South Dakota, North Dakota, and Oklahoma) within the Heartland Region participated in the first of three IHP Learning Collaborative workshops in April 2013.

Participants represented school nurses, state school nurse consultants, healthcare providers, parents and advocates, and special education teachers. A satisfaction survey was completed to determine the effectiveness of the session and provide feedback to support improvement of the process. The results found the following:

- 76.4% of the participants were highly satisfied with the LC experience including:
  - Effective leadership from the Heartland team (89.8%);
  - Establishing a learning environment where opinions of members were valued (82.1%); and
  - Identifying work that could have a concrete impact on a real problem (87.2%).

Baseline data was collected from the LC participants to determine both the cohesiveness of the local teams and their perceptions on the current effectiveness of the IHP teams in their communities. The results found that the LC participants rated their teams positively, specifically including the following:

- High ratings of trust among team members (79.5%);
- Named leadership (78.4%); and
- Commitment from their local organization (59%).

Many areas of improvement of local IHP practices were identified by LC participants. Baseline information on the current quality of the IHP in local communities was rated:

- 40% of the participants rated the effectiveness of the IHP process as good or higher;
- 50% indicated a collaborative team participated in the IHP process;
- 60% agreed that IHP contained information that informs user of specialized services or emergency procedures;
- 60% agreed that the IHP reflect the student and family's desired outcomes;
- 20% felt that their school's current criteria were identifying students in need of an IHP;

- 50% of the participants rated the assessment and diagnostic process as below standard; and
- 60% of the participants were somewhat or not satisfied with their IHP's development and use.

Each community will develop an implementation plan to improve practices in their educational systems based on the strengths and needs of their community. Project implementation will be the work of subsequent years.

## INCREASE HEARTLAND PEDIATRIC GENETICS PROVIDERS' KNOWLEDGE OF AND PRACTICE BEHAVIORS IN HEALTHCARE TRANSITION FOR YOUTH WITH GENETIC CONDITION.

**Key Finding:** Genetics team staff provide insight to help build an integrated transition system which helps to define the specialist role.

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### Supporting Evidence

#### Transition Project

The first phase of a tripartite strategy to clarify the role of the genetics team in the healthcare transition of genetic patients was initiated in 2011-2012 and was concluded this year. In 2011-2012, representatives from two Heartland states partnered with the National Health Care Transition Center (NHCTC) to develop procedures to support youth transition to adult health care services as part of learning collaborative. The work of the learning collaborative resulted in participating genetic clinics integrating transition components of the health care transition process into their clinics. A second outcome of that work was the implementation of a pediatric genetics service provider's survey to determine their knowledge, attitudes and practice behaviors regarding health care transition. (Detailed description and evaluation finding from these projects can be found in the Heartland Collaborative 2010-2011 Annual Report).

This year, the final activity of the first phase of the project, a qualitative study, was completed. Its purpose was to: 1) observe and describe the roles of the genetics teams; 2) how they had come to define and respond to the health care needs of their patient population, 3) how they address issues of transition for their patients; and 4) inquire as to the challenges they face in

meeting these needs. In an effort to frame the complexities of the transition process and to observe how they are being addressed, staff in five genetics clinics across five states (e.g., South Dakota, Nebraska, Iowa, Oklahoma and Arkansas) within the Heartland were interviewed. A total of 49 staff from diverse backgrounds (e.g., geneticists, genetics counselors, nurse practitioners, parent/family liaisons, dieticians, developmental pediatricians, and social workers) participated in structured interviews. The information and experiences obtained from the activities from the first phase of work will be used as a foundation for the regional transition activities planned in 2013-2014.

The following summarizes the findings from the qualitative study that was completed in 2013.

**Medical Context.** In order to better understand transition issues for youth with special health care needs, it is important to understand the context of genetic services for children and youth. Currently in the Heartland region, patients typically travel great distances to the appropriate clinic. It means their patients typically return home to a limited set of health and health related services in their local/rural communities. It also means that many clinics operate “outreach” clinics across their respective states – at great cost in terms of staff time and resources. Finally, several interviewees made the point that, unlike genetics practices in east coast states, it is possible, even probable, that a clinic will see many of the same patients over an extended period of years. Indeed, it is possible to see the children of previous patients.

Geneticists/teams clearly recognize the complexity of needs and issues and the need for ongoing (life-long) supports for the patient in terms of their family. They all recognize the great need for facilitating the “transition” from pediatric to adult care. Where they differ is their recognition and response to their patient’s needs relative to things such as school, social service needs and/or to employment. Different sites and their medical teams have responded to these questions in different ways. In particular, where the resources are available, social workers and parent/family liaison staff have been added to the medical teams to support families and youth as they plan for their transition.

**Current Strategies.** The results of the interviews provided insight to the current strategies that were implemented. Most clinics utilize a team approach contributing to their coordination, referral, and problem-solving capabilities. In some clinics, transition responsibilities were assumed by a designated person such as an advanced practice nurse, social worker, genetics counselor, or other member of the team. A major focus of these genetics clinics was sharing

information and resources about transition possibilities, services, and systems navigation. Genetics clinics facilitate coordination and communicate with primary care providers by sharing clinic reports, providing consultation, and helping with care management. The genetics medical team often provided input to school systems by sharing clinic reports, informing and empowering families, participating in Individualized Education Plan meetings, and encouraging school involvement in clinics.

A significant contribution of the geneticist is the ability to plant seeds regarding transition at a very early age at the time of diagnostics and during initial and on-going services. A primary function of the genetics medical team was encouraging family expectations and connecting them with the information and resources to advocate for services and supports on their child's behalf. In some clinics, a parent navigator was an effective addition to provide peer support and assist families with systems navigation. Emphasis was often placed on promoting the independence and self-advocacy skills of the youth themselves both in and out of clinic.

**Current Challenges.** Despite the many good things going on in the area of transition, it is not uncommon for these services to end at age 21. The complexities of the disability service system and the inherent challenges in the availability and quality of transition services from school to adult life impose challenges in knowing and accessing available resources. Many clinics compensate by continuing to provide services beyond 21 or offering adult clinics. Multiple issues impact these service delivery practices:

- No one person is identified with the specific role and designated responsibility for overseeing transition services.
- Billing and reimbursement rates are limiting in that many of the activities essential to transition are not billable or have restrictions as to who can bill and how much time can be submitted.
- Clinics often report that individuals come for initial diagnostic services and often again later when they are planning children themselves leaving a gap during the critical transition years.
- The shortage of adult providers, primary care and geneticists, makes transitioning anywhere difficult. This is especially true for those low incidence conditions that adult providers may lack the knowledge or experience to work with.



- Transition is locally driven, necessitating linkages back to an individual's home community impacting the consistency, quality, and responsiveness with which services are delivered.

**Recommended Considerations [both general and specific].** Based on the qualitative study a number of recommendations were identified to support improved transition practices:

- Develop a team-based transition model that can integrate the big picture approach with the specialist by acknowledging the contribution of the specialist and their critical role to the broader system.
- Clearly define transition roles and responsibilities of the team members.
- Develop an assessment process that informs a transition action plan.
- Anticipate barriers to transition that can be addressed by the genetics' team.
- Address system's barriers related to adequate billing procedures for adults.
- Expand expertise and transition practices of the Heartland region to bring together work groups to address transition to develop effective implement strategies.

**HRSA Priority 3:** Expand the pool of the genetic service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties and educators.

### INCREASE PRIMARY CARE PROVIDERS' ACCESS TO TOOLS AND RESOURCES FOR THE BASIC EVALUATION AND FOLLOW-UP MONITORING OF THE GENETICS PATIENT.

**Key Finding:** PCPs gained knowledge and accomplished their identified goals through participation in the Collaborative Partners Project.

**Key Finding:** Resources were developed to be used in PCP practices that provide just-in-time information.

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#### Supporting Evidence

##### Collaborative Partners Project

In 2011, five primary care physicians (PCP) participated in a Heartland Collaborative Partners Program. This project recruited from the eight heartland states. PCPs were selected who were interested in learning more about newborn screening (NBS) and would promote NBS resources



within their practices and professional societies. These PCPs met at the American Public Health Laboratories (APHL) Genetic Testing and Newborn Screening Symposium meeting with NBS representatives from the Heartland states to meet their “partners” and exchange information and resources. Each PCP developed a plan for NBS education to their peers. The NBS coordinator served as a resource for the PCP.

In order to evaluate the results of the project, PCP and NBS coordinators from each of their states completed a follow-up (one year post) survey. There was a 60% return rate for PCPs and 80% for state coordinators. The results of the PCP survey found that overall they gained knowledge about NBS (67%-agreed and 33%-strongly agreed) and knowledge in genetics (33%-agreed and 37%-strongly agreed). The project provided a context for developing new relationships. Follow-up data suggested that the PCPs were able to accomplish the goals that they set at the meetings (33%-agreed and 37%-strongly agreed). One participant felt that more actions needed to be identified in the planning process, which would have maximized the benefits. PCPs disseminated information in their states related to NBS. This was accomplished through presentations and dissemination of materials. In addition, all PCPs were active members of NBS/Genetics advisory/policy committees in their states. The majority (67%) would recommend participation in the project to their colleagues.

The results of the state newborn screening coordinators survey found that overall the coordinators discovered additional resources that would be helpful for the PCPs and developed new relationships with the PCP in their state (50% agreed and 50% somewhat agreed). The majority would recommend this project to other primary care providers (25% strongly agreed and 50% agreed). They noted several successes of the program. PCPs assumed additional roles related to genetics and NBS in their communities (e.g., participation on the AAP planning committee to develop the Genetics in Primary Care web series, assuming an advocacy role by sharing information about NBS, and presenting at annual PCP meetings). The coordinators also reported an overall increase of PCP awareness of genetics and newborn screening as it pertains to primary care. Recommendations for project improvements included having more time to for PCPs to network by creating time for follow-up meetings and identifying ways for increased networking between the physicians. One coordinator recommended expanding the project to include PCP professional organizations.

## DETERMINE NEEDS OF PRIMARY CARE PROVIDERS TO IMPROVE CARE FOR PATIENTS WITH GENETIC CONDITIONS WITH A FOCUS ON CLINICAL MANAGEMENT.

**Key Finding:** Needs assessment results found that PCPs serve a variety of children with genetic disorders and need resources to support their delivery of quality services.

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### Supporting Evidence

#### Clinical Services Work Group Needs Assessment

The Heartland Collaborative's Clinical Services Work Group developed a needs assessment survey to further clarify the needs of our region's primary care providers and pediatricians caring for patients with genetic conditions, with a focus on clinical management guidelines and/or checklists for monitoring patients with genetic conditions.

Local chapters of the American Academy of Pediatricians (AAP), the American Academy of Family Physicians, and the National Association of Pediatric Nurse Practitioners (NAPNAP) partnered to distribute the surveys. A diverse perspective of primary care providers from the Heartland Region was hoped to be obtained by approaching these large healthcare provider member organizations. The survey was also shared with the clinic sites participating in the Genetics in Primary Care Institute's (GCPI) Quality Improvement Project. The survey was available on SurveyMonkey™, a secure online survey tool, from May 20, 2013 through August 30, 2013. A total of 3783 email blasts with the electronic survey were distributed with a total of 125 returned surveys for a 3.3% return rate. The following results should be interpreted with caution give the low return rate as it may not be a representative sample.

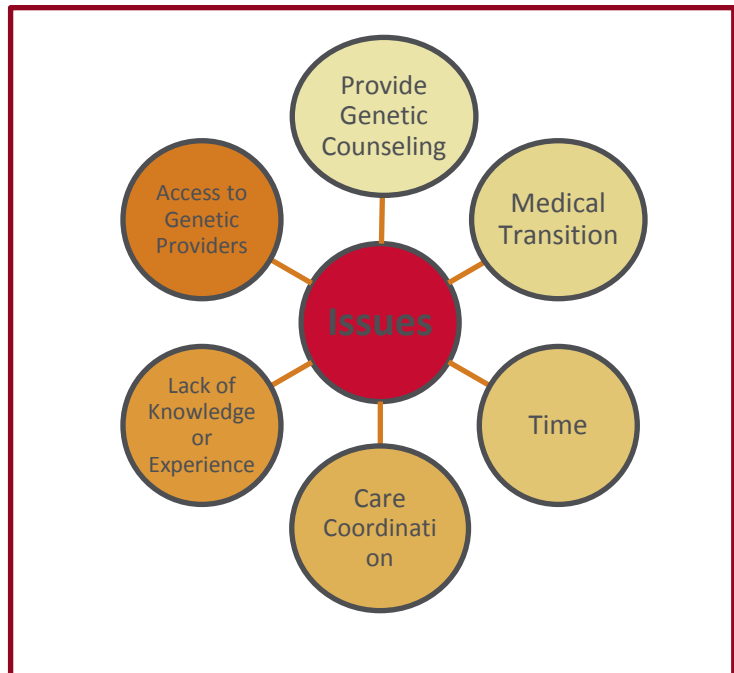
The results found that 96% of the respondents reported seeing patients with genetic conditions. Eighty-nine percent of participants reported seeing patients with Down syndrome, making it the most commonly seen genetic condition. Cystic fibrosis (45%), sickle cell anemia (42%), and neurofibromatosis (41%) were the next most common. Table 1 summarizes the most commonly seen genetic conditions reported by this group. It is clear from this data that the majority of primary care providers in the Heartland region were caring for patients with a wide variety of genetic conditions. When asked what genetic conditions were taking the most time to manage, Down syndrome was again on top at 63%.

**Table 1: Genetic Conditions seen most Often by PCPs**

| ANSWER OPTIONS  | RESPONSE PERCENT | RESPONSE COUNT |
|---|------------------|----------------|
| Angelman syndrome                                     | 15.6%            | 17             |
| Becker muscular dystrophy                             | 6.4%             | 7              |
| Cystic Fibrosis                                       | 45.0%            | 49             |
| Down syndrome   | 89.0%            | 97             |
| Duchenne muscular dystrophy                           | 13.8%            | 15             |
| Fabry disease   | 0.0%             | 0              |
| Fragile X syndrome                                    | 24.8%            | 27             |
| Gaucher disease                                       | 0.9%             | 1              |
| Galactosemia  | 9.2%             | 10             |
| Hemophilia  | 17.4%            | 19             |
| Klinefelter syndrome                                  | 15.6%            | 17             |
| Medium-chain acyl-CoA dehydrogenase (MCAD) deficiency | 13.8%            | 15             |
| Neurofibromatosis                                     | 41.3%            | 45             |
| Phenylketonuria (PKU)                                 | 10.1%            | 11             |
| Sickle cell anemia                                    | 42.2%            | 46             |
| Thalassemia   | 22.0%            | 24             |
| Turner syndrome                                       | 31.2%            | 34             |
| Other (please specify)                                | 31.2%            | 34             |
| <i>answered question</i>                              |                  | <b>109</b>     |

Participants were asked what they find most challenging about treating children and/or adults with genetic conditions. Key themes are presented in Figure 1. Lack of access to genetics services/providers arose as a broad challenge. For those providers who have had patients evaluated by a genetics provider (geneticist or genetic counselor), 77% (81/105) feel that they were given enough information to feel comfortable monitoring these patients. Of those providers who feel they did not get enough information, one Arkansas physician stated “A letter

**Figure 1: Summary of Issues**



explaining medical issues related to genetic condition would be nice attachment to dictation to help referring physician.” A Kansas physician said, “I haven’t been given any protocols to follow.” One Missouri physician stated, “I don't feel comfortable knowing what to monitor alone.”

Fifty-four percent of respondents reported that they currently have clinical guidelines and/or checklists that they use to manage their patients with genetic conditions. Of those respondents who are currently using clinical management guidelines, 73.5% reported that the guidelines are meeting their needs in caring for patients with genetic conditions. However, 26.5% of respondents using these guidelines are not satisfied. One Arkansas physician stated, “It's hard to coordinate who is doing what. Does the geneticist order these tests? Do I?” One Kansas physician reported, “Not really readily available - and some worry that the paper guidelines (or guidelines in books like the Wilson /Cooley book) may be outdated - so look stuff up through PubMed or on the KU genetics website.” Other physicians reported that there just not enough of such guidelines available, with one Nebraska physician stating, “It would be helpful if there were more for other genetic conditions.” Of the 34% of respondents that do not use such clinical guidelines and/or checklists, 88% (44/50) reported that they would find these helpful.

The vast majority (68%) of respondents feel that their clinic/practice are effectively coordinating care and treating the health care needs of children and youth with special health care needs. However, 27.8% of respondents disagreed or strongly disagreed that their clinic/practice is effectively coordinating the care of children and youth with genetic disorders, and 19.4% disagreed or strongly disagreed that their clinic/practice is effectively treating the healthcare needs of children and youth with genetic disorders. These numbers are clear indication that there is significant room for improvement in the care of children with genetic conditions in the primary care setting.

### **Just-In-Time Materials: Hemoglobinopathy Trait Pilot Project**

Considerable effort, at both local and national levels, have been expended to create primary care physician aimed action sheets, information sheets, podcasts, and other “just in time” learning materials to support counseling related to genetic conditions. The Hemoglobinopathy Trait Pilot project had two phases: needs assessment and product development. The data gathering phase included a survey to the state’s primary care providers who care for newborns to: 1) determine their attitudes toward their counseling needs; 2) identify related financial

barriers; and 3) identify factors that prevent them from providing the counseling at the primary care level. Information from the survey helped to inform the development of a CME web-based “micro-CME” session. The videos regarding newborn hemoglobinopathies were developed and are now online. They can be found directly on YouTube by searching for the terms “childrensomahacme” or “Just in Time CME”. They can also be accessed from the website that people will access for CME credit, [www.childrensomaha.org/medicaleducation](http://www.childrensomaha.org/medicaleducation).

## ENHANCE THE HEARTLAND’S EARLY HEARING DETECTION AND INTERVENTION (EHDI) PROGRAMS THROUGH RESOURCE SHARING AND EDUCATION.

**Key Finding: The EHDI Program Exchange resulted in changes in implementation practices.**

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### Supporting Evidence

#### EHDI Program Exchange

The EHDI Program Exchange was implemented to support states’ improvement of their EHDI programs. Identified objectives that were developed through a self-assessment process guided the development of the site technical assistance visit agenda. Four states (i.e., Iowa, Oklahoma, Missouri, and Nebraska) participated in the program exchanges which included one and a half days of consultation. Consultation varied by site based on the individual state’s self-assessment and identified objectives.

The first step in the evaluation of the project included interviews with the participants. They viewed these technical assistance strategies as very beneficial. Specifically, participants reported that:

- These site visits were more beneficial than other learning opportunities, e.g., conferences, workshops, informal networking they have experienced. The intentionality of the visit, coupled with exposure to new practices and meeting with multiple project staff, all contributed to the added value of this technical assistance approach.
- There were also unanticipated benefits for the visiting participants as a result of the program exchange.

Focus group informants described specific changes in practices or infrastructure supports that resulted as a result of the program exchange:

- New strategies to engage hospitals as partners in EHDI resulted in a positive change in hospital referrals. Reduced referrals were of benefit as the better trained hospital staff resulted in fewer false positive assessments.
- Increased linkages with primary care providers were developed through distribution of PCP packets that provided guidance about their role in failed screening follow-up. This has the potential for improved child assessment follow-up.
- Recommendations from one program exchange resulted in the state allocating resources to hire a data manager. This additional human resource will support implementation of management strategies of the site they visited, potentially resulting in an improved follow-up data system.

Follow-up data will be collected in Spring 2014 to further determine benefits of the exchange.

A second strategy for the EHDI work group was to increase state EHDI coordinators' understanding of genetics as it relates to hearing loss. A total of four EHDI coordinators from the Heartland Collaborative participated in an online course, Genetics and Hearing Loss for EHDI professionals. The majority of the participants rated the course positively (i.e., very good to outstanding) in a variety of areas including:

“It helped me to understand the impact of genetic testing on families in ways I hadn't thought of before.”

.....EHDI Coordinator

- Course content (100%);
- Effectiveness of the online presentations and relevance of readings (100%);
- Relevance to professional goals (100%);
- Relevance of activities and assignments (87.5%);
- Opportunity for networking (100%); and
- Effectiveness of the technical assistance (87.5%).

Overall, participants commented that the course was challenging. As one participant said, “I found it to help connect some of the dots so I can see that I have a lot more information to learn and share with providers and families in my state.” The resources that were provided were

immediately useable in their states. It also revealed some of the gaps in genetic testing and counseling available in some states. The parent panel helped to increase awareness of the impact of genetic testing and diagnoses on the families. Very little input was provided to improve the course, as it overall met the needs of the participants. Some suggested the course could place more emphasis on how to work with families and less on the technical aspects of genetics.

A third strategy priority was to have state EHDI coordinators' participate in a webinar series. Sixty-four participated in the first of the two-part series on the Genetics of Hearing Loss. Although this webinar targeted EHDI's coordinators, it was open to any interested participant.

**HRSA Priority 4:** Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services.

HEARTLAND WILL INITIATE AN INFORMATION SYSTEM TO FACILITATE HEARTLAND STATES' ADOPTION OF (SECRETARY'S ADVISORY COMMITTEE ON HERITABLE DISORDERS IN NEWBORNS AND CHILDREN) SACHDNC RECOMMENDATIONS RELATED TO NEWBORN AND CHILD SCREENING AND GENETIC FOLLOW-UP AND TREATMENT SERVICES.

**Key Finding:** Heartland states piloted Critical Congenital Heart Defects (CCHD) screening in their states and the majority were planning implementation of Severe Combined Immunodeficiency (SCID) screening.

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## Supporting Evidence

### CCHD and SCID Screening for Newborns

Much work has been completed in Heartland states to further the implementation of CCHD and SCID screening for newborns. All eight states have participated in partial implementation of CCHD, that is, screening was provided under pilot studies or on voluntary bases by some hospitals. Only two states reported partial implementation of SCID. The majority (75%) of the states were at a planning level for implementation of SCID. Two states, Oklahoma and Iowa, have applied for grant funding to further their implementation of SCID screening. Heartland supported states in a number of activities to further the implementation. Four states had



representatives at the SACHDNC meeting. In order to support the states work in this area, a SCID Implementation Toolkit was developed and disseminated. It currently is available on the Heartland Regional Collaborative website: <http://www.heartlandcollaborative.org/scidtoolkit>.

**HRSA Priority 8:** Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.

IMPROVE STATE SYSTEMS TO REFLECT BEST PRACTICES IN LTFU BY INCREASING THE SPECIFICITY OF NEWBORN SCREENING, ESTABLISHING AN APPROACH TO THE LONG-TERM FOLLOW-UP OF PATIENTS, INCLUDING INCORPORATING ELECTRONIC HEALTH INFORMATION, AND EXPANDING THE NUMBER OF CONDITIONS FOR WHICH SCREENING TESTS ARE AVAILABLE.

**Key Finding: Heartland states are participating in two national follow-up projects.**

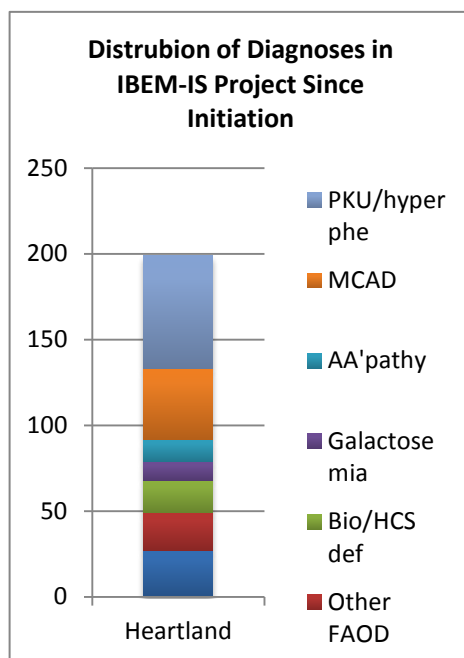
## Supporting Evidence

### Case Definition Pilots

Four states (i.e., Iowa, Kansas, Nebraska, and Missouri) have participated in the LTFU case definition pilots. Participation in these pilots will help to facilitate the states adoption of case definitions for the recommended uniform screening panel.

### Inborn Errors of Metabolism-Information System (IBEM-IS) Project

In 2004, Region 4 formed a Medium chain acyl-Coenzyme A dehydrogenase deficiency (MCADD) work group to address long-term follow-up for inborn errors of metabolism. This effort was led by Dr. Sue Berry of University of Minnesota. The problem the work group planned to address was the lack of an evidence base for treatment protocols for rare metabolic disorders, including MCADD. From this work group, the IBEM-IS project formed. The project's



purpose was to develop a long-term follow-up database and to track the treatments, health, and developmental outcomes of the patients.

In this project, each visit of an enrolled patient is entered into the database. To date, four Heartland centers (Nebraska, Oklahoma, South Dakota, and Missouri) have participated. Nebraska is the only state required to report to the Heartland Regional Collaborative. This year they have enrolled 109 patients, with 81 under the age of 18 and 28 older than 18. There has been 87 intake surveys entered. The figure displays by diagnosis the cumulative number of patients enrolled (slightly under 200) from Heartland's first enrollment through March 2013.

**HRSA Priority 10:** Any other program priority that addresses the needs of the region and the program goals.

## EXPAND THE IMPLEMENTATION OF THE GENETIC SYSTEMS ASSESSMENT (GSA).

**Key Finding:** The GSA was refined and instrumentation is in process of being finalized.

### Supporting Evidence

#### Genetic Services Assessment Project

The Genetic Services Assessment project continued activities in metrics refinement and stakeholder input. The metrics were refined and scoring scheme was developed according to findings from the implementation trials in the eight Heartland states. Two stakeholder webinar conferences were held with the goals to: (1) review metrics and scoring based on implementation findings; (2) develop strategies for the national roll-out; and (3) identify potential measures for the next version. Stakeholders identified partnership organizations that will help facilitate the roll-out and specified expected outcomes. Development of strategies for national dissemination began during 2013 and is continuing into 2014. The metrics and scoring scheme are currently being developed into an instrument that can be adopted and administered nationally.

#### Hispanic Families Access to Genetic Services

**Key Finding: Key barriers to access to genetic services by Hispanic families were identified through a needs assessment process.**

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## **Supporting Evidence**

Due to the growing Hispanic population in the Midwest region [ranging from 49% to 114% increase (2010 census)], the Heartland Collaborative supported the initiation of the Hispanic Access project. The goal of this project was to identify the barriers to accessing genetic services for Hispanic patients and to identify strategies to support genetic service providers in providing culturally competent quality care.

The first phase of the needs assessment was completed through interviews with twenty individuals [e.g., genetic service providers, primary care providers who serve Hispanic children and outreach coordinators from the states' Children and Youth with Special Health Care Needs (CYSCN) and family support systems who serve Hispanic families]. Four states were represented in these interviews.

The request for input was favorably received with high levels of interest in collaborating with the Heartland Collaborative in any capacity related to this process. The needs assessment was successful in identifying key barriers to access to genetic services by Hispanic families including: finances, lack of transportation, translated materials and bilingual staff, language, culture and fear of immigration services. An outgrowth of this needs assessment is a recommended second phase that will include the implementation of a needs assessment survey with Hispanic families throughout the region and the emergence of an advisory board from participants that were interviewed. Evaluation of the access to culturally competent genetic services will be completed following the implementation of recommended strategies based on the participatory needs assessment process.

**FACILITATE COMMUNICATION AND LINKAGES OF HEARTLAND PROVIDERS THROUGH A VARIETY OF METHODS.**

**Key Findings:** Heartland Collaborative disseminates findings of their work using multiple modalities.

**Supporting Evidence**

**Dissemination of information and Resources via Web-Based Venues**

The Heartland Collaborative used a variety of strategies to disseminate information including a

list serve and website. The Heartland Collaborative has online searchable databases for clinical services and advocacy resources. All Heartland project reports are posted on the Heartland website as well as the funded projects.

Two quarters were compared to see the usage trend across time. There were

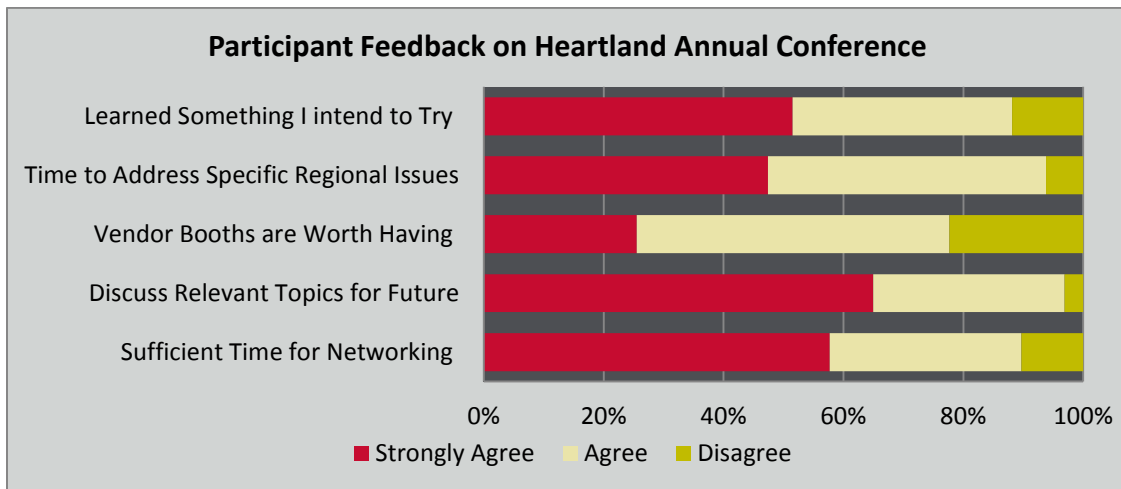
high levels of activity on the Heartland Regional Collaborative website during both quarters. However there was a decrease in use in the spring compared to the fall. In both quarters there were high percentages of new visitors and an increase of individuals accessing the site by mobile devices.

| <b>A Comparison of Web Traffic across Years: from September 1 - April 30, 2013</b> |                               |                              |                       |
|--|-------------------------------|------------------------------|-----------------------|
| <b>CATEGORIES</b>  | <b>9/1/2012 to 12/31/2013</b> | <b>1/1/2013 TO 4/30/2013</b> | <b>PERCENT CHANGE</b> |
| <b>Total Visits:</b>   | 1142                          | 1031                         | -9.7                  |
| <b>Visit per Day:</b>  | 9.2                           | 8.6                          | -28.5                 |
| <b>Total Page Views:</b>   | 2957                          | 2115                         | -28.5                 |
| <b>Page Views per Day</b>  | 23.9                          | 17.6                         | -35.2                 |
| <b>Average Page Views Per Visit:</b>   | 2.6                           | 2.1                          | -20.8                 |
| <b>Unique Visitors</b>   | 787                           | 832                          | 5.6                   |
| <b>Percent of New Visitors</b>   | 39                            | 24                           | 36.7                  |
| <b>Accessed by Mobile Phone</b>  | 1.86                          | 1.77                         | -4.8                  |
| <b>Percent of Ne Mobile Visitors</b>   | 77.8                          | 80.9                         | 3.9                   |

## Annual Conference

An annual conference is sponsored each year to allow for educational opportunities and networking for participants. This past year it was held in St Louis, Missouri. The following is a summary of participant evaluation of their satisfaction of the conference.

The Heartland Regional Conference was rated positively. Comments suggested that the networking was valuable and most topics were relevant and interesting. Vendor booths were rated as less helpful. Conference participants suggest that the topics and speakers were interesting. As one participant indicated, “..... has been one of the best conferences I have attended at Heartland.” One suggestion was to add lab topics to the agenda.



## NATIONAL EVALUATION

The Heartland evaluator and administrative team partnered with other regional collaboratives (RC) and NCC/RC national evaluation team to identify a core set of common evaluation measures that could be used across all the regional collaboratives. Heartland participated in the three day NCC/RC sponsored evaluation meeting in Washington DC and in biweekly phone conference meetings to support the development of a national evaluation plan. Draft documents were reviewed and comments were provided to support the refinement of the process. Potential providers and family members were identified who could be respondents as

part of the effort to collect baseline efforts. Heartland Regional Collaborative has activities that could be measured on the common measures in the following areas:

### Common Measures for YEAR 1 National Requirements

| HRSA RC Guidance Priorities                      | Priorities in Generic Terms                | Regional Collaboratives With Year 1 Activity                         | Measures   |
|--|--|--|--|
| 1. Treat in the context of a medical home        | <b>Access</b>                              | Heartland<br>MSGRC<br>NEGC<br>NYMAC<br>Region 4<br>SERC<br>WSGSC     | HRSA MCHB Performance Measure 41 – RCs reported activities   |
| 4. Build state public health department capacity | <b>Newborn Screening Capacity Building</b> | Heartland<br>MSGRC<br>NEGC<br>NYMAC<br>SERC<br>WSGSC                 | Level of state institutionalization of RUSP, e.g. CCHD and SCID<br><br>RC activities in support of RUSP  |
| 5. Strengthen public-private partnerships        | <b>Collaborations</b>                      | MSGRC<br>NYMAC<br>NEGC<br>Region 4<br>SERC<br>WSGSC                  | # of family/disease-specific advocacy groups that RCs reach<br><br># of family/disease-specific advocacy groups that RCs work collaboratively with                         |
|  | <b>Affordable Care Act Implementation</b>  | Region 4,<br>NEGC,<br>NYMAC<br>WSGSC                                 | # of unique hits accessing ACA sections on RC websites<br><br># of educational modules e.g., webinars other materials and disciplines of participants                      |
| Transition from pediatric to adult care          | <b>Access</b>                              | Heartland,<br>MSGRC,<br>NEGC,<br>NYMAC<br>Region 4,<br>SERC<br>WSGSC | # of practices (e.g., specialty care and primary care practices) impacted by RC transition activities<br><br># of unique hits accessing transition sections on RC websites |

The Evaluation Work Group sought to use existing measurement protocols for the evaluation. The HRSA Performance Measure Form #41, Medical Home was used by the RCs to capture data on their medical home activities. In partnership with the RCs, the NCC collected data from the RCs' constituencies with a Working Together instrument [Working Together: A Profile of Collaboration (Chrislip & Larson, 1994)] that had previously been used by the Heartland RC's Advisory Board. The sources of the protocols selected for the national evaluation include the Children with Special Health Care Needs Survey (CSHCNS) developed by HRSA, the Medical Home Index (MHI) developed by the Center for Medical Home Improvement and a transition preparation question from Got Transition!. Comparisons of Heartland data and National aggregate data can be found in the following tables. Table 2 summarizes regional members' participation in RC activities, e.g., work groups. Heartland has good proportion of consumers/families participating in activities. A higher percentage of consumers/family members participate in workgroups than in the annual meeting.

| Table 2.  |  |  |                         |  |
|---|--|--|-------------------------|--|
| COUNTS OF PEOPLE AND ORGANIZATIONS THAT THE RC WORKS WITH     |  |  |                         |  |
|   | PROVIDERS<br>(MD, PA, RN,<br>Public health,<br>etc.) | CONSUMERS<br>(Affected<br>Individuals &<br>Family members) | FAMILY<br>ORGANIZATIONS | DISEASE-SPECIFIC or<br>ADVOCACY<br>ORGANIZATIONS |
| # on RC<br>mailing list                                       | Range: 48-<br>2,756                                  | Range: 12-30   | Range: 0-102            | Range: 1-285                                     |
|   | <b>Heartland: 70</b>                                 | <b>12</b>  | <b>0</b>                | <b>1</b>   |
|   | Total: 4,257   | Total: 124   | Total: 108              | Total: 334                                       |
| PARTICIPANTS IN RC ACTIVITIES                                 |  |  |                         |  |
| # who attended<br>RC annual<br>meeting                        | Range: 23-133  | Range: 0-16  | Range: 0-7              | Range: 0-10                                      |
|   | <b>Heartland: 44</b>                                 | <b>5</b>   | <b>0</b>                | <b>2</b>   |
|   | Total: 386   | Total: 58  | Total: 19               | Total: 15  |
| # who<br>participate on<br>RC workgroups<br>and<br>committees | Range: 0-300   | Range: 0-35  | Range: 0-9              | Range: 0-26                                      |
|   | <b>Heartland: 99</b>                                 | <b>10</b>  | <b>0</b>                | <b>0</b>   |
|   | <b>Total: 712</b>                                    | <b>Total: 108</b>  | <b>Total: 27</b>        | <b>Total: 50</b>                                 |

The Heartland Collaborative has sponsored a number of in-person and webinar presentations for members in their region. The largest number of participants engaged in presentations related to the medical home. Presentations related to newborn screening had the next highest number of participants. Results are summarized in Table 3.





| <b>Table 4. WEBSITES AND SOCIAL MEDIA</b>  |  |                              |                       |   |  |                   |
|--|--|------------------------------|-----------------------|---|--|-------------------|
| <b>WEBSITES</b><br>(Specific Website Sections by the following HRSA RC Grant Priorities) |  |                              |                       |   |  |                   |
|  | <b>Medical Home</b>  | <b>NBS Capacity Building</b> | <b>Collaborations</b> | <b>Affordable Care Act Implementation</b> | <b>Newborn Screening Long Term Follow up</b> | <b>Transition</b> |
| RC website has pages that address these topics (Y/N)                                     | Y-2  | Y-1                          | Y-1                   | N/A                                       | Y-2  | Y-1               |
| If yes, # of unique visits   | 251  | 134                          | 831                   |   | No data collected                            | 27                |
| If yes, # of page views  | 386  | 175                          | 975                   |   | No data collected                            | 39                |
| If yes, # of links used  | No data collected  | No data collected            | No data collected     |   | No data collected                            | No data collected |
| If yes, # of materials downloaded  | No data collected  | No data collected            | No data collected     |   | No data collected                            | No data collected |
| <b>SOCIAL MEDIA</b>  |  |                              |                       |   |  |                   |
| RC uses Social Media (Y/N)   | Yes  |                              |                       |   |  |                   |
| If yes, please indicate type AND Number Of unique followers                              | FACEBOOK: _____<br>TWITTER: _____<br>PINTEREST: _____<br>OTHER: _____ You-tube _____ |                              |                       |   |  |                   |
| If yes, # of Posts related to:   |  |                              |                       |   |  |                   |
| If yes, # of Reposts   |  |                              |                       |   |  |                   |

The Heartland Collaborative has an active website that has content related to medical home, newborn screening capacity building, newborn screening long term follow-up and transition. The only area of content not addressed at this point is the Affordable Care Act implementation. The highest number of web ‘hits’ were related to collaboration content. The Heartland currently is not using diverse social media strategies to communicate with its constituencies. Results are summarized in Table 4.

All Heartland region states have CCHD screening being completed in either pilots or on a voluntary basis by selected hospitals. The majority of the states are just at a planning level for SCID screening. Results are summarized in Table 5.

| Table 5  |                  |                   |                  |                   |
|--|------------------|-------------------|------------------|-------------------|
| STATE/TERRITORIAL ADOPTION OF CCHD AND SCID RUSP<br>(As of June 2013)  |                  |                   |                  |                   |
|  | CCHD<br>National | CCHD<br>Heartland | SCID<br>National | SCID<br>Heartland |
| Universal  | 13               |                   | 11               |                   |
| Partial  | 26               | 8                 | 5                | 2                 |
| Planned  | 7                |                   | 24               | 6                 |
| No Activity  | 6                |                   | 12               |                   |
| Total:   | 52               |                   | 52               |                   |
| <b>Universal:</b> Screening is provided for all newborns<br><b>Partial:</b> Screening is being provided under pilot studies or on a voluntary basis by some hospitals<br><b>Planned:</b> State is considering<br><b>No Activity:</b> Not under consideration |                  |                   |                  |                   |

### Working Together: The Degree of Collaboration within the Heartland Collaborative

The Working Together instrument was designed to evaluate the effectiveness of collaboration efforts across five areas (context, structure of the group, effectiveness of the members, collaboration process, and results of collaboration efforts). The Heartland RC had used this instrument and recommended it be utilized in the national evaluation. It was administered by the NCC through SurveyMonkey™ to 20 members of the advisory boards and working groups that collaborate with the RCs. The response rate was 75% (n=15).

Overall the RCs scored positively on the five components of the Working Together instrument. Based on a four-part scoring system (1 = True; 2 = More True than False; 3 = More False than True; 4 = False) and by calculating a percentage that rated the item as true, it was learned that most respondents found that the context for the collaboration to be well-timed and responsive to the issues. The results found that the timing is right to address newborn screening and genetic issues and the collaborative is responding to those critical issues facing the field (100% true). As for the structure of the RCs, it was learned that the respondents felt that while stakeholders

have agreed to work together (67% true) and they had effective means of communications (79% true) and access to the expertise for effective meetings (57% true), there was a need for more clearly defined roles (50% true).

There is high trust among the RC participants as evidenced on the following item: Members sufficiently trust each other and accurately share information, perceptions and feedback. The effectiveness of the collaborative process is advanced by strong leadership (69% true). However, respondents said that it was less likely for participants to reflect on how well the collaborative members are working together (39%).

As for the results of the collaborative effort, fewer respondents said that they can devote the necessary effort to achieve their goals. The time and effort of the collaboration is directed at obtaining the goals, rather than keeping itself in business (43% true). In addition, when asked about whether there is an established method for monitoring performance and providing feedback on goal attainment, the respondents indicated that there was room for improvement. (46% true).

## SUMMARY

The Heartland Genetics Services Collaborative actively engaged partners to increase access to and improve the quality of genetic and NBS services in the region. The work was completed under the leadership of the HRCC and the Heartland Advisory Board. The Heartland Collaborative invested in education and technical assistance to build the capacity of health care providers, public health professionals, university faculty, children, and family members. Opportunities to participate in research continued to be a high priority as states collaborated in regional and national research projects. System capacity building was addressed through a number of projects, ranging from piloting innovative practices to building a quality indicator assessment system. Overall, the results indicated that the Heartland Collaborative has implemented a wide array of activities that successfully addressed its overall project goals.

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\*Supported (in part) by grant T73MC00023 from the Maternal and Child Health Bureau,  
Health Resources and Services Administration, Department of Health and Human Services.

\*Supported in part by grant 90DD0601 from the Administration on Developmental  
Disabilities (ADD), Administration for Children and Families, Department of Health and  
Human Services.

