University of Nebraska
Medical Center

HEARTLAND
GENETICS SERVICES
COLLABORATIVE

Heartland Genetics Services Collaborative: Annual Report

2013-2014

December 2014

Interdisciplinary Center for Program Evaluation

Collaborate Evaluate Improve

PROGRAM DESCRIPTION: 2013-2014

The Heartland Genetics Services Collaborative (referred to in the remainder of the report as Heartland Collaborative) is a network of representatives (parents, patients, clinicians, researchers, industry representatives, laboratorians, and public officials) from eight states. This ten-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 Collaborative Regional Coordinating Center (HRCC) with planning and direction supported by the Heartland Collaborative Advisory Board and three work groups [e.g., Newborn Screening (NBS), Clinical Services, and Advocacy] and through a grant (H46MC24089) 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.

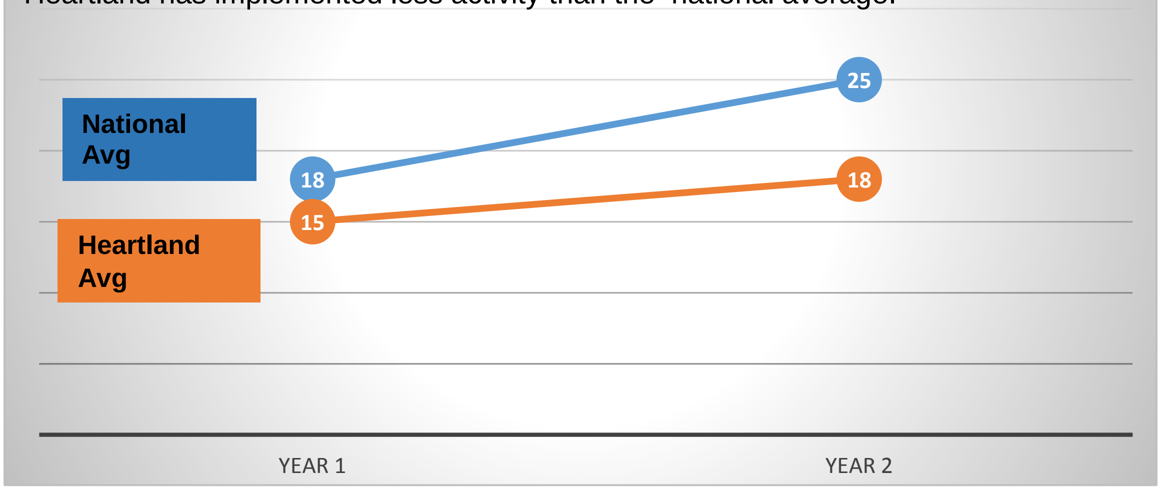
Heartland Collaborative Evaluation Findings

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 a 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.

Cross Project Efforts to Support Medical Home

As part of the national evaluation, the Heartland Collaborative rates the degree to which they assisted in developing, supporting, and promoting medical homes for the Maternal Child Health (MCH) populations (HRSA pm #41). Heartland Collaborative increased the number of activities in this area this past year, including work in transition, the Affordable Care Act (ACA) and support of primary care providers. Heartland Collaborative has less effort in this area than the national average.



Heartland Collaborative demonstrated a **20%** increase in Medical Home activities in Year 2.

Heartland has implemented less activity than the national average.

Individualized Healthcare Plan (IHP) Learning Collaborative 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 supported state teams to share, critique, evaluate, and create practices, policies, and resources that will promote strategies to improve student outcomes.

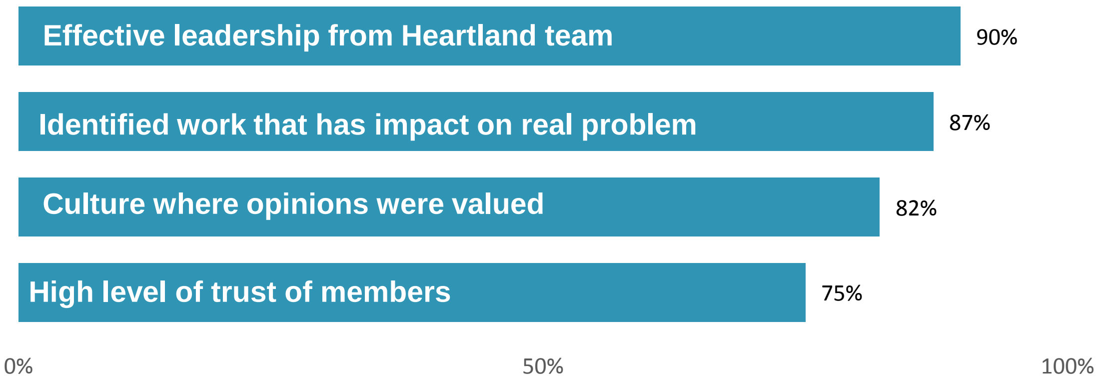
The IHP Learning Collaborative (LC) participants from the eight Heartland Collaborative states (Kansas, Iowa, Nebraska, Missouri, Arkansas, South Dakota, North Dakota, and Oklahoma participated in a series of two in-person meetings, five webinars, local team meetings, and various follow-up conference calls. These learning opportunities spanned across a year's period of time. Participants represented school nurses, state school nurse consultants, healthcare providers, parents and parent professional advocates, special education teachers and school administrators

Over the course of the project, two strategies were used to evaluate the project. A satisfaction survey was administered to determine the effectiveness of the sessions and provide feedback to support improvement of the process, and interviews of selected state team members were completed at the conclusion of the Learning Collaborative.

At the start of the LC work, participants reported that the current IHP process in their states had room for improvement with participants rating the overall the IHP process as low (60%). Few IHP team members rated their implementation process as effective and identified several areas for improvement (baseline data). They viewed LC as a means to improve the systems in their states.

IHP LC teams rated the quality of their states' IHP implementation as low and viewed the LC as a **means to improve systems** in their state.

Teams were highly satisfied with the LC experience.



In the summer of 2014, a cross section of participants of the IHP LC were interviewed to provide input on how well the Learning Collaborative had worked for them. A semi-structured interview process was completed with team leaders of each state or a team member. Analysis was completed by reviewing the documents and identifying emergent themes. A total of six team members were interviewed as part of this process.

The Structure

Team Composition Provided for Different Perspectives

Each state was asked to bring a team to the IHP Learning Collaborative as part of the process. All eight states participated in the IHP process with a total of 51 team members. Representatives of the teams varied slightly, but across the teams, there were consistently a school nurse, parent, and state school nurse consultant. Other team members included a genetic counselor, special education representative, and/or a family advocate. Having teams with varied perspectives was felt to be very valuable. It was very helpful to hear the different perspectives within each state's own team, as well as, to learn from the individuals across the teams. The teams were motivated to do the work and were very self-directed. Assignment of a team leader was critical to the success of the process. For some teams, there was some inconsistency of team members' availability, which somewhat interrupted the process.

Having team members with **varied perspectives** was valuable to the process.

In-Person Meeting Structure Worked Well

Overwhelmingly, the group thought the in-person meetings were very helpful and as one participant said, "Stimulating." It was suggested that having the designated time away from the day-to-day activities helped them focus on the work. The webinars, however, had a mixed review. One participant reported that the first conference calls and working webinars were not as robust as some of school nurses would like them to be, but they improved over time. Most felt that the educational webinars, particularly on FERPA, were very helpful.

Structure of the Work in the States Varied

Many of the teams attempted to meet periodically in between the formal LC meetings. Some did this with more regularity than others. For those that did not have consistent meetings, time was the contributing factor. One group suggested that having individual team meetings prior to the Learning Collaborative activities was a very helpful solution when they found they had difficulty bringing their group together. The conference call served as a means of keeping the states on track with their work in between IHP LC meetings. At the time of the interview, most were determining what their next steps in the process would be. They reported that they will turn to Heartland Collaborative for support as they plan their implementation strategies.

The Process

Heartland Collaborative Facilitators were Very Flexible

The participants were impressed with the flexibility of the Heartland Collaborative facilitators and their willingness to reframe and redirect the process based on feedback. The initial aims of the LC shifted and that was "ok" as it was the right direction to move the group. It was

Communication was the key to the successful collaborative process.

….a IHP team member

viewed as a “learning experience”. For example, at first the goal was to develop a common IHP format, but after discussion, it was felt it became “clear this wouldn’t work practically.” The emphasis then shifted to tools or strategies that would help a district fine tune their own process. “Clarity” emerged as part of the LC process.

Effective Teaming Evolved over Time

Overall, the learning collaborative process worked very well over time with effective communication being the key to success. It took time for the team members to work cohesively as a group. The sense of being a team took time as most teams had not worked together prior to this experience. Because members were new both to the state teams, as well as across state teams, group dynamics played a role in the process. It was “obvious that the group needed time to gel” so that they could begin to develop trusting relationships. As the process unfolded and the teams began to work together, participants felt that the process helped to broaden the people’s views of each other and the work that they do.

What were the IHP LC outcomes at the state and local level?

Information was disseminated, and providers were trained.

- Statewide training was presented based on the materials and information shared at the Learning Collaborative. Continuing Education Units (CEUs) were available for school nurses for the statewide training.
- The Maternal Health Division purchased some of the resources used in LC so that they could be disseminated within the state.
- Materials were posted for dissemination on participant’s websites.
- CDC 1305 grant in one state has incorporated information from the Learning Collaborative on the section that addresses IHP as part of their collaborative work with the school nurse. The nurses are being trained on children’s chronic diseases (obesity, asthmas, and diabetes) and IHP development.

Parents were engaged as part of the local and state process.

- Steps were taken to have parents become more engaged as advocates within local organizations’ advisory groups.
- Parents gained information to support their advocacy work.
- Steps were initiated to change practices at the local level.
- At a local level, an IHP process was improved based on information from the LC and was being used with students and families.
- One team planned to use the information to connect Newborn Screening efforts with school health.

Next Steps

The LC recommended two primary strategies as next steps for the IHP work. First, a work group was established that included parent representatives to develop a toolkit of resources that can be used by all of the stakeholders of the IHP LC. It is anticipated that this resource will be completed during the 2014-2015 grant year. The second recommendation was to develop a research project based on the work of the IHP. This research project will be developed in 2014-2015.

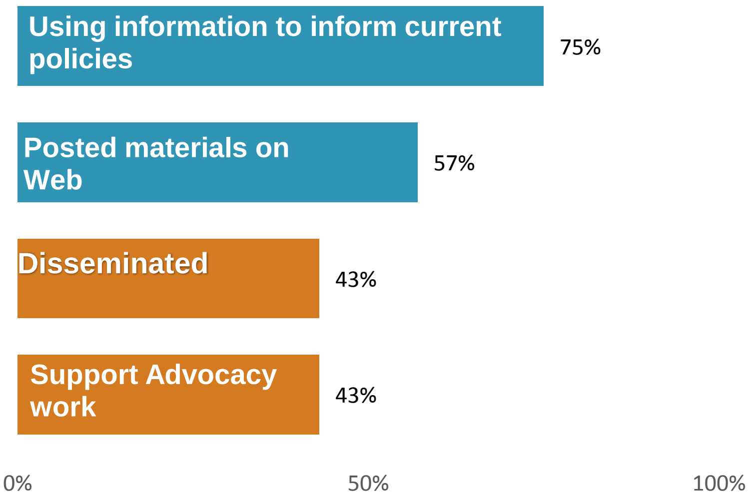
Affordable Care Act (ACA) Forum

Heartland Collaborative sponsored a two-phase training series on the Affordable Care Act (ACA) with three main purposes: (1) provide education to our target population, key stakeholders that serve this population, as well as healthcare providers in order to advance their knowledge on ACA; (2) identify concerns with the ACA as it relates to this population that may be common among states in the region; and (3) learn from stakeholders and decision makers how the Collaborative can address the identified concerns. Phase one included an educational webinar on ACA. Phase two was a one-day face-to-face meeting which included an overview of ACA and breakout sessions for participants to engage in discussions in order to give recommendations on how Heartland Collaborative may be able to address any identified concerns in their respective states. Invited stakeholders included Title V directors, Medicaid directors, University centers for Excellence in Developmental Disabilities (UCEDD) directors, Leadership Education in Neurodevelopmental Disabilities (LEND) directors, Heartland Collaborative advocates, Early Hearing Detection and Intervention (EHDI) coordinators, state insurance commissioners, state genetics coordinators, state NBS coordinators, state genetics clinicians, state's Family-2-Family executive directors, and the state school nurse consultants.

The interactive nature of the format allowed for a combination of presentation and discussion, which helped bring diverse perspectives and experiences to the discussion. The forum helped to ground participants on the issues around access, coverage, and care that the families and patients in the Heartland Collaborative face. Forum participants used some of the following words to describe their experience: "informed, hopeful, connected, inspired, energized, encouraged, and motivated." The result of the discussions identified next steps for the Heartland Collaborative including: 1) data to show impact at the local level; 2) education materials appropriate for the different audiences (professionals vs patients); and 3) leadership role for the Collaborative.

Evaluation of the ACA training was obtained through a follow-up survey. A total of seven participants provided feedback with the majority finding the ACA workshop and webinar as informative. Overall, the participants put the information presented into action in their state to inform policies, disseminate materials, and to support advocacy work.

The ACA Forum resulted in action as state level planning was initiated.



Over 75% of the participants strongly agreed that the ACA Forum resulted in increased knowledge about ACA and its related policies.

Transition Project

The purpose of this project was to identify the role of the genetics medical team in health care transition for youth with genetic and chromosomal conditions and utilize that information to formulate a health care transition model that addresses the complex issues experienced by genetics service providers and patients. To accomplish this goal, a learning community was established that had members across all Heartland Collaborative states and representatives from the New York Mid-Atlantic Consortium for Genetic and Newborn Screening Services (NYMAC).

Transition Learning Collaborative Helps to Inform Practices

Webinars and face-to-face meetings were the two primary strategies used to help inform practices and to develop a health care transition model. During this grant year, three webinars and two in-person meetings were conducted. The work resulted in the following two products:

- Developed a working model illustrating the role of the geneticist in health care transition to guide research and development activities.
- Developed three documents: 1) Social Capital “Asset Building,” 2) Social Capital “Opportunity Development,” and 3) Social Capital “Connecting Activities” for use in building the “bridges” needed for successful health care transitions.

Parents Provide Input to Improve Transition Processes

Interviews with parents of young adults with different genetic conditions were completed to determine strategies that could improve the transition process. These resulted in the following lessons learned:

- Pediatricians and children's hospitals continued to serve as a resource as they transitioned to new hospitals or care providers.
- It is important to have access to information by specialty nurses, and if things didn't follow a predictable path, provided information on why.
- A transition coordinator was exceptional in helping families find an adult provider with whom the family was genuinely comfortable and confident.
- It is important to start planning early. Things went well if that happened.
- Finding a physician that had empathy for the family's situation is important.

Ongoing challenges to making effective transitions include:

- Insurance coverage for their child-now-young adult was, and is, a great concern.
- It was very challenging to go from being the central caregiver and being included in every aspect of what was going on in their children's health care—to having a much more reduced and limited role.
- Parents were looking for a family-centered approach that is often missing or even purposefully ignored.
- Parents often had concerns about the youth's own willingness—not simply readiness—to make the transition.
- Even after knowing whom to go to for health care, it is hard finding the time to schedule appointments and then travel to a diverse set of providers.
- Often there is a significant lack of coordination between the primary care provider and the specialists/subspecialists needed.
- Many healthcare providers seem to be unwilling to share healthcare information with schools/teachers for fear that the patient will be stigmatized.

Recommendations from the parents suggested the components for a toolkit that could help parents and their youth in the transition journey.

Transition Information was Disseminated

Information from the Transition Learning Community resulted in a number of products and dissemination activities which are described in the following:

- Presented "Transitioning and Medical Home: The Role of the Geneticist" at the *Got Transition? and Health Care Transition: Research Symposium* at the MD Anderson Cancer Center in Houston, Texas on October 16-18th, 2013.

- Participated in monthly National Coordinating Center (NCC) Transition Workgroup meetings.
- Co-presented at the National Society of Genetics Conference pre-conference workshop including two sessions entitled “Heartland Collaborative Region Transition Projects: Overview and Findings” and “Supported and Customized Employment: What are the Possibilities for Youth with Genetic Conditions”? in Anaheim, CA.

Future Evaluation

Evaluation of the Transition Learning Community will be completed in the next grant year to answer the following questions:

- Did the learning collaborative approach accomplish its objectives and what were the lessons learned?
- What is the current state of the art/practice in medical education related to teaching about “health care transitions” and the role of geneticists, in particular?
- How do Adult Care providers operationalize and communicate their expectations of transitioning patients and determine what their practical needs might be?

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

Early Hearing Detection and Intervention (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 intentionality of the visit, coupled with exposure to new practices and meeting with multiple project staff, contributed to the added value of this technical assistance approach.

> Exchange programs were viewed as more beneficial than traditional training and technical assistance with both parties of the exchange benefitting.

Focus group informants described specific changes in practices or infrastructure supports that directly result from 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 Primary Care Physician (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.

At one-year follow-up (spring 2014), additional benefits were reported with states accomplishing the following:

- Increased linkages with the genetics community were established by changing process in Genetics Advisory EHDI standing committee in order to better address the issues of children with genetic related hearing loss.
- Enhanced data system between eleven hospitals and Public Health System used by EHDI program has improved exchange of information and data analysis capacity.
- Dissemination of hospital reports created by the Center for Disease Control (CDC)-funded Newborn Hearing Screening Program (NHSP) Quality Assurance/Data Coordinator allowed NHSP to identify babies who were not screened by hospital location and to subsequently provide targeted training and support to specific hospitals that have high “Refer” (did not pass), “Not Performed,” and “Not Reported Rates.”
- One state was concerned with their 1-3-6 month follow-up rates which were 98%, 39%, and 41% respectively. Modeling another state’s process, a fax-back system with PCPs for infants lost following a “refer” was initiated. This new procedure resulted in improved EHDI long term follow-up. The state’s 1-3-6 month follow-up rates improved to 98%, 57%, and 60% respectively.

Long-term follow-up rates were greatly improved by implementing another state’s procedures.

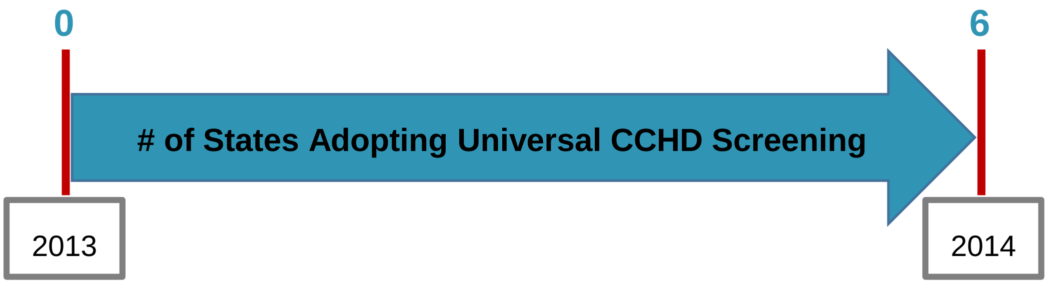
HRSA Priority 4: Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services.

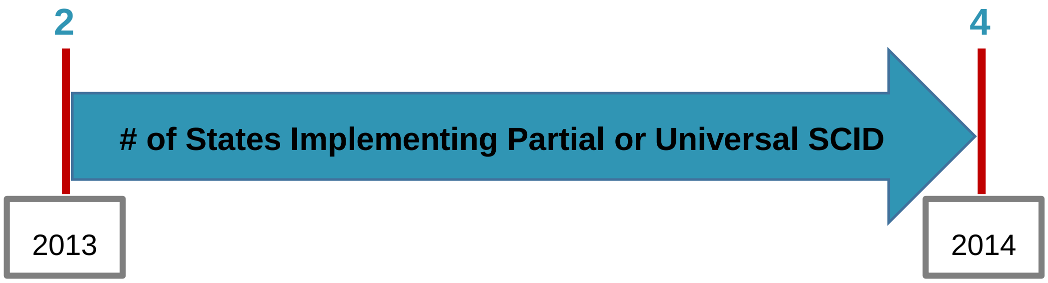
Critical Congenital Heart Defect (CCHD) and Severe Combined Immunodeficiency (SCID) Screening for Newborns

Much work has been completed in Heartland Collaborative states to further the implementation of CCHD and SCID screening for newborns. Across the region, states have improved their implementation status of both CCHD and SCID. Iowa 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 Collaborative website: http://www.heartlandcollaborative.org/scidtoolkit.

Majority of states have adopted universal CCHD screening.

States have made progress in adopting CCHD screening over the past two years.





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.

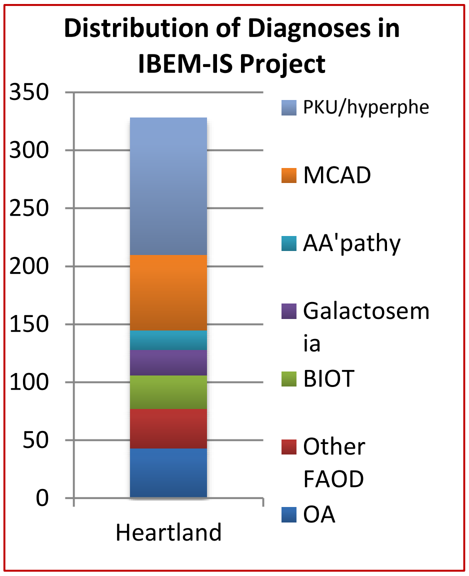
Case Definition Pilots

Four states (i.e., Oklahoma, South Dakota, Nebraska, and Missouri) participated in the Long Term Follow-Up (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

The project's purpose is to develop a long-term follow-up database and to track the treatments, health, and developmental outcomes of the patients with inborn errors of metabolism.

In this project, each visit of an enrolled patient is entered into the database. The figure displays, by diagnosis, the cumulative number of patients enrolled (328) through November 2014. The majority of the patients were diagnosed with PKU (36%) or MCAD (20%).



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

Genetic Services Assessment Project

The Genetic Services Assessment (GSA) project completed the metrics development process with the main deliverable, the GSA tool version 2.0. The metrics and associated scoring scheme of the tool are based on findings from the implementation trials in the eight states in the Heartland Collaborative and additional input from public comment and stakeholders. A plan for GSA tool dissemination was developed in 2014, identifying regions to target for further implementation. Discussions about tool implementation are ongoing with partners from two other regions.

Hispanic Families Access to Genetic Services

Due to the growing Hispanic population (ranging from 49% to 114%) in the Midwest region (2010 census), the Heartland Collaborative supported the initiation of the Hispanic Access project. The goal of this project is 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. In the first year of the project twenty conversations with key stakeholders were completed in an effort to identify the issues surrounding access and provision of culturally competent medical genetics services. Barriers to access that were reported included: financial difficulties, lack of transportation and cost of services, language issues, culture differences, and fear of immigration services.

Based on the information obtained from these interviews, Heartland Collaborative initiated the implementation of a qualitative research project in 2014 to determine to what extent Hispanic families that are primarily Spanish speaking, experience problems in accessing genetic services and specialty care for their children with genetic conditions.

Heartland Collaborative received IRB approval from UAMS on April 2014 to interview approximately eighty families in these four states. This process involved the development of a questionnaire, informed consent information sheet, and a flier to recruit families. Recruitment of families began in April in the state of Oklahoma, with nine in-person interviews conducted in Spanish in the month of May.

The remainder of the interviews in three states and the analyses will be completed in 2014-2015.

Dissemination of Information and Resources via Web-Based Venues

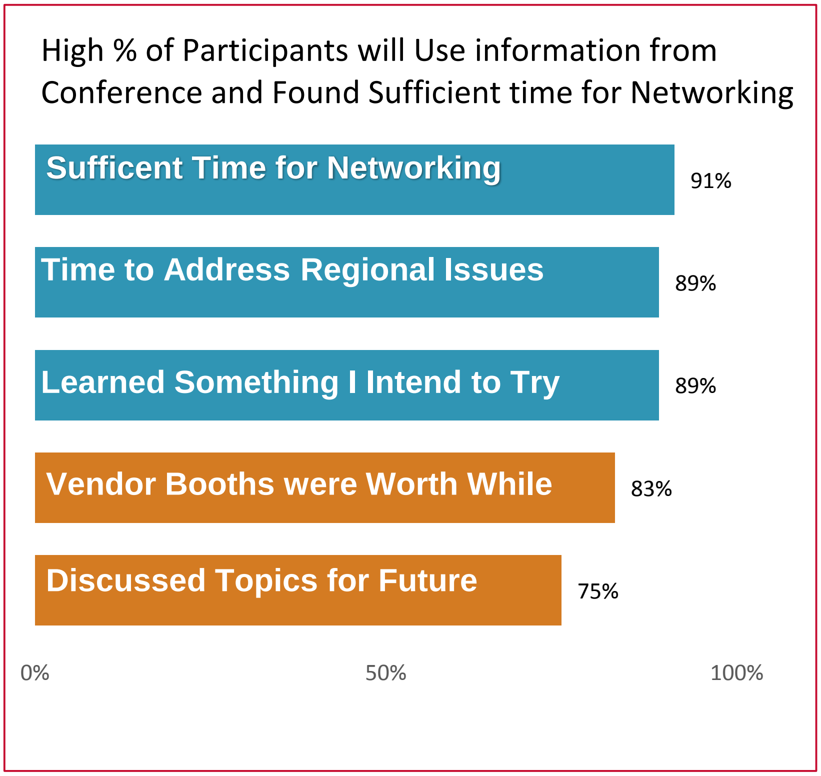
The Heartland Collaborative used a variety of strategies to disseminate information including a list serve and website. The Heartland Collaborative has online searchable databases for clinical services and advocacy resources. All Heartland Collaborative project reports are posted on the Heartland Collaborative website, as well as the funded projects. This year, Heartland Collaborative revised its website design to maximize its usability for professionals, families, persons with genetic disorders, and the general public. HRSA is interested in how individuals are using the website in light of five priority areas: medical home, NBS capacity building, collaboration, ACA, and NBS long term follow-up. The results found that individuals are primarily accessing the Heartland Collaborative web for information on the medical home or for purposes of collaboration. A recent upsurge was related to ACA.

Individuals access the Heartland Collaborative website primarily for information on Medical Home.

	Medical Home	**Newborn Screening Capacity Building**	**Collaborations**	**ACA Implementation**	**NBS Long Term Follow-Up**	**Transition**
RC website has pages that address these topics (Y/N)	Y	Y	Y	Y	Y	Y
If yes, total # of unique visits	1594	208	1250	410	40	200
If yes, # of page views	2356	317	949	600	40	338
U-Tube Visits	114	610	148	24	22	
Home page visits	Total: 4650	By State: 4215 (48 States)	By Territory, including DC: 153 (DC)	Total Foreign Countries: 282	Top three foreign countries UK, 41; Canada, 33; India, 29	

Heartland Collaborative Annual Conference

An annual conference is held each year to allow for reporting of the work of the Collaborative, educational opportunities, and networking for participants. This past year it was held in Kansas City, Missouri. A change in format that included preconference meetings (e.g., NBS meeting and Transition Learning Collaborative) resulting in the highest attended annual conference (129 participants) in the history of the Heartland Collaborative. The attendees represented individuals from the Heartland Collaborative work groups, advisory board, projects, and consultants, as well as some attendees that were from outside of the Heartland Collaborative region. The following is a summary of participant evaluation of their satisfaction of the conference.


High % of Participants will Use information from Conference and Found Sufficient time for Networking

The Heartland Conference was rated positively. The change in format was viewed favorably as the separate days for workshops allowed for increased time for collaboration, networking, problem - solving and opportunity to identify practical strategies and resources. Overall, the ratings and comments suggest that the conference was very beneficial for participants.

> I enjoyed networking with people from different professions and reasons for participating. It shows how true collaboration should work between all providers (medicine, education and families).
>
> ……..a conference participant

Summary of Heartland Collaborative Data for National Common Measures - YEAR 2

The Heartland Collaborative evaluator and administrative team partnered with other regional collaboratives (RCs) and NCC/RC national evaluation team to identify a core set of common evaluation measures that could be used across all the RCs. Heartland Collaborative participated in the NCC/RC sponsored evaluation meeting in Washington DC and in monthly phone conference meetings to support the implementation of the national evaluation plan. Comparisons of Heartland Collaborative data and National aggregated data can be found in the following tables.

Heartland Collaborative has higher proportion of consumers/families participating in activities than the National Regional average.

A similar % of families are represented across types of activities.

	PROVIDERS	**CONSUMERS**	**FAMILY ORGANIZATIONS**	**DISEASE-SPECIFIC or ADVOCACY ORGANIZATIONS**
# on RC mailing list	**Heartland %: 74%**	**9%**	**2%**	**1%**
	Heartland: 92	**11**	**2**	**1**
	All Regions: 4257 89%	124 3%	143 3%	334 7%
PARTICIPANTS IN RC ACTIVITIES				
# who attended RC annual meeting	**Heartland %:** **87%**	**11%**	**1%**	**1%**
	Heartland: 113	**14**	**1**	**1**
# who participate on RC workgroups	**Heartland %: 91%**	**9%**		
	Heartland: 99	**10**	**0**	**0**

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 and collaboration.

In-Person (I), Webinars (W), and Teleconferences (T)*

	Medical Home			**NBS Capacity Building**			**Collaborations**			**ACA Implementation**			**NBS Long-Tern Follow-Up**			**Transition from Pediatric to Adult Care**		
	I	W	T	I	W	T	I	W	T	I	W	T	I	W	T	I	W	T
# Events/Sessions	2	5		1			1			1	1		1			1	3	
Total # of participants	53	84		25			122			17	29					53	52	
Participants by Type: For participants other than consumers, please indicate participant's professional discipline (not job title).																		
Consumer (affected individuals & family members including representatives of family & disease-specific organizations)	20	19					18			3	3					10		
Genetic counselor (Masters trained)	7	7					9				3					9	16	
Other genetic services provider		1					1			2	5					1	2	
Medical geneticist							7				1					2	3	
Non-geneticist specialty physician (e.g., endocrinologist)							12									12	15	
Primary care physician	1	6					4									2	1	
Other healthcare provider (e.g., RN, midwife, phlebotomist)	15	13																
Social service provider (e.g., MSW)							2									6	4	
Public health genetics professional	4						2			9	4							
Public health non-genetics professional	3	18					7									1		
Newborn screening professional (e.g., laboratory, follow-up staff)		2		25			38			2	13		25			2	3	
Legislator or legislative staff																		
Other (please specify)	3	18					22			1	1					8	8	

Heartland cross-trained providers, parents and consumers across all HRSA priorities.

Title	Date	Target Audiences	Topics Addressed
Individualized Health Plans (A series of 2 in-person sessions and numerous teleconferences/webinars plus 1 educational webinars) as part of the Learning Collaborative	7/1/2013 – 2/26/2014	Genetic counselors, parents, school nurses, state administrators, physicians	State and local implementation of IHP process including emphasis on children with genetic or NBS disorders
Affordable Care Act (ACA)	5/6/2014 & 5/22/2014	Consumers, genetics providers,	Review the key elements of the ACA.
Healthcare Transition (A series of 2 in-person and 3 webinars) as part of the Learning Collaborative	10/25/2013-4/23/2014	Medical genetics, providers, and counselors.	Implementation of the transition process for youth with genetic and NBS disorders.
NBS Follow-Up Webinar	11/13/2013	Medical genetics, providers, and counselors; NBS professionals.	Provided information on SCID and Pompe screening
NBS Workshop (NBS Capacity)	4/22/2013	NBS professionals	SCID and Pompe screening (national and regional perspectives); Emerging Topics

Heartland Activities Demonstrate the Need for Regional Collaboratives

Area: NBS Laboratory Emergency Preparedness

Who was involved: All Heartland States and Minnesota

Why the activity had to be regional? States must go outside their boundaries in emergencies to get the necessary back-up laboratory resources, so there is a need to build capacity across states.

Benefits of regional approach: The structure of the Regional Collaboratives allows for pilot projects, where the defined project size is manageable and determines its effectiveness. The regional and national networks make it feasible to expand these pilots to other regions and nationally. This provides for a cost effective approach that would be more difficult to replicate without the regional and national networks in place.

What was accomplished: Heartland Collaborative established a reliable NBS back-up testing for all states in Heartland and Minnesota. They built a strong collaboration among the states in Heartland. The laboratories presented our successes to other Regions and NCC. Our template and approach have been the basis of Preparedness workshop in most (all) other regions.

Area: NBS Exchange (EHDI)

Who was involved: Oklahoma, Kansas, Arkansas, Iowa, and Nebraska

Why the activity had to be regional? Since the EHDI coordinators have distinct roles within their states, it is necessary for them to reach outside of their state borders for technical assistance and training. The Heartland network provides a natural mechanism to match state coordinators in order to maximize their learning from colleagues in similar roles across states.

B**enefits of regional approach**: A targeted technical assistance approach allows for states to identify their needs and link with states where there are innovative, best practices that they can learn from and adopt in their state. A regional approach allows for states to take advantage of states who have dealt with similar issues.

What was accomplished? The exchange resulted in a number of specific changes in practices or infrastructure supports including:

- 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.

Area: Networking and Mentorship in Learning Community Projects (Individualized Health Plan, Transition)

Who was involved: NYMAC, New York, Maryland, District of Columbia, and all Heartland States. Physicians (specialists and primary care providers), advocates/parents, transition coordinators, genetic counselors, school nurses, state school nurse consultants, and special education leaders.

Why the activity had to be regional? The Learning Community Projects embrace projects in new areas that few states have embarked. As a result, taking an approach that entails bringing multiple stakeholders across geographically similar states provides an environment that increases the exchange of ideas that would not be possible by states working within their borders. Typically what works in one state is applicable in another, which saves resources, time, and helps infuse evidence-based practice quicker.

Benefits of regional approach: Having the Heartland Collaborative provide the infrastructure support, facilitate the group process, provide support to find additional resources, help to keep the process moving and hold the group accountable for developing and implementing state plans that can potentially result in changes at the system and local area.

What was accomplished? A number of preliminary outcomes were accomplished for the two learning collaboratives that have just completed their first year including:

Transition Learning Collaborative:

- The preliminary results found there were new people at the table discussing medical transition that were not there before both in the service delivery and research communities. For example, Heartland representatives participated in the National Coordinating Center Work Group meeting held in person in March 2014. They were part of a major discussion about research and service delivery of transition and how this would work with specialty providers in the area of transition. They will become part of the next research academy that will look at new research directions.
- Overall, there is more credibility in the field about health care transition than ever before as a result of the multi-layered impact of the work of the Heartland. They have interjected the role of genetic specialists into the health transition that has not been there before.

IHP:

- Statewide training was presented based on the materials and information shared at the Learning Collaborative. CEUs were available for school nurses.
- In one state, materials were posted for dissemination on participant's websites.
- Steps were taken to have parents more engaged as advocates within local organizations' advisory groups.
- CDC 1305 grant in one state has incorporated information from the Learning Collaborative on the section that addresses IHP as part of their collaborative work with the school nurse. The nurses are getting trained on health related topics on children's chronic diseases (obesity, asthmas and diabetes) and IHP development.

---

41 **PERFORMANCE MEASURE** ***HEARTLAND COLLABORATIVE DATA***	The degree to which grantees have assisted in developing, supporting, and promoting medical homes for MCH populations. **Goal 3: Ensure Quality of Care** **(Develop and promote health services and systems designed to improve quality of care)** **Level: National** **Category: Medical Home**
GOAL	To increase the prevalence of medical homes within the systems that serve MCH populations.
MEASURE	The degree to which grantees have assisted in developing and supporting systems of care for MCH populations that promote the medical home.
DEFINITION	Attached is a set of five categories with a total of 24 elements that contribute to a family/patient-centered, accessible, comprehensive, continuous, and compassionate system of care for MCH populations. Please use the space provided for notes to describe activities related to each element and clarify reasons for score.
HEALTHY PEOPLE 2010 OBJECTIVE	Related to Objective 16.22 (Developmental): Increase the proportion of CSCHN who have access to a medical home.
DATA SOURCE(S) AND ISSUES	Attached is a data collection form to be completed by grantees. The data collection form presents a range of activities that contribute to the development of medical homes for MCH populations.
SIGNIFICANCE	Providing primary care to children in a “medical home” is the standard of practice. Research indicates that children with a stable and continuous source of health care are more likely to receive appropriate preventive care and immunizations, less likely to be hospitalized for preventable conditions, and more likely to be diagnosed early for chronic or disabling conditions. Data collected for this measure would help to ensure that children have access to a medical home and help to document the performance of several programs, Including EPSDT, immunization, and IDEA in reaching that goal.

DATA COLLECTION FORM FOR DETAIL SHEET #41 *HEARTLAND COLLABORATIVE DATA*

Using the scale below, indicate the degree to which your grant has assisted in the development and implementation of medical homes for MCH populations.

0	**1**	**2**	**3**	**Element**
Category A: Establishing and Supporting Medical Home Practice Sites				
NA				1. The grantee has conducted needs and capacity assessments to assess the adequacy of the supply of medical homes in their community, state, or region.
NA				2. The grantee has recruited health care providers to become the medical homes.
NA				3. The grantee has developed or adapted training curricula for primary care providers in the medical home concept.
	1			4. The grantee has provided training to health care providers in the definition and implementation of the medical home and evaluated its effectiveness.
	1			5. The grantee has assisted practice sites in implementing health information technologies in support of the medical home.
	1			6. The grantee has developed/implemented tools for the monitoring and improvement of quality within medical homes.
	1			7. The grantee has disseminated validated tools such as the Medical Home Index to practice sites and trained providers in their use.
	1			8. The grantee has developed/implemented quality improvement activities to support medical home implementation.
Category A Subtotal (possible 0-24): **5**				
Category B: Developing and Disseminating Information and Policy Development Tools: The grantee has developed tools for the implementation of the medical home and promoted the medical home through policy development				
NA				9. Referral resource guides
	1			10. Coordination protocols
	1			11. Screening tools
	1			12. Web sites
NA				13. The grantee has developed and promoted policies, including those concerning data-sharing, on the State or local level to support the medical home
NA				14. The grantee has provided information to policymakers in issues related to the medical home
Category B Subtotal (possible 0-18): **3**				

0	1	2	3	Element
Category C: Public Education and Information Sharing: The grantee has implemented activities to inform the public about the medical home and its features and benefits				
	1			15. The grantee has developed Web sites and/or other mechanisms to disseminate medical home information to the public.
	1			16. The grantee has provided social service agencies, families and other appropriate community-based organizations with lists of medical home sites.
NA				17. The grantee has engaged in public education campaigns about the medical home.
Category C Subtotal (possible 0-9): **2**				
Category D: Partnership-Building Activities				
			3	18. The grantee has established a multidisciplinary advisory group, including families and consumers representative of the populations served, to oversee medical home activities
		2		19. The grantee has coordinated and/or facilitated communication among stakeholders serving MCH populations (e.g., WIC, domestic violence shelters, local public health departments, rape crisis centers, and ethnic/culturally-based community health organizations)
NA				20. The grantee has worked with the State Medicaid agency and other public/private sector purchasers on financing of the medical home.
	1			21. The grantee has worked with health care providers and social service agencies to implement integrated data systems.
Category D Subtotal (possible 0-12): **6**				
Category E: Mentoring Other States and Communities				
	1			22. The degree to which the grantee has shared medical home tools with other communities and States.
	1			23. The degree to which the grantee has presented its experience establishing and supporting medical homes to officials of other communities, family champions, and/or States at national meetings
NA				24. The degree to which the grantee has provided direct consultation to other States on policy or program development for medical home initiatives
Category E Subtotal (possible 0-9): **2**				

0 = Not Met 1 = Partially Met 2 = Mostly Met 3 = Completely Met

Total the numbers in the boxes (possible 0-72 score) ____18_____

Evaluation Report prepared by
Barbara Jackson*, Ph.D.
Interdisciplinary Center of Program Evaluation

The University of Nebraska Medical Center's
Munroe-Meyer Institute: A University Center of
Excellence for Developmental Disabilities

***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.**