University of Nebraska Medical Center

HEARTLAND
GENETICS SERVICES
COLLABORATIVE

Heartland Genetics Services Collaborative: Annual Report

2014-2015

March 2016

Interdisciplinary Center for Program Evaluation

Collaborate Evaluate Improve

PROGRAM DESCRIPTION: 2014-2015

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 -12-year-old Collaborative actively engages with its partners at a regional and national level to increase access to and improve quality of genetic and newborn screening (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.

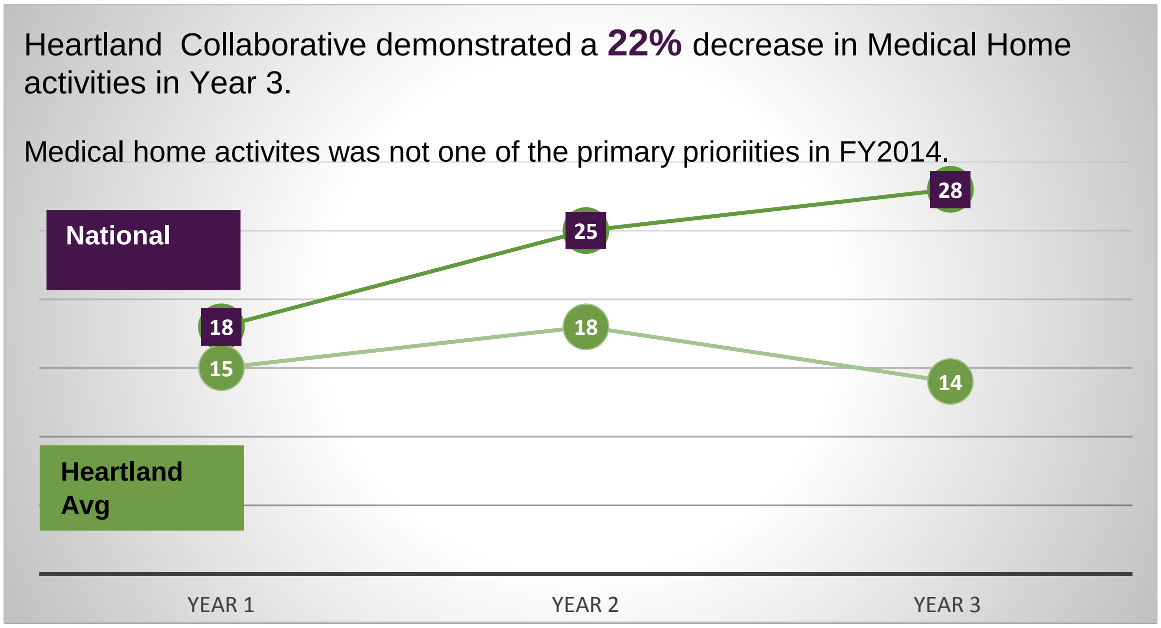
Heartland Collaborative Evaluation Findings

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 decreased the number of activities in this area this past year since their Individualized Health Plan project was delayed. IHP implementation will occur in 2016. Priorities this year focused primarily on telehealth, transition, access to services, and needs assessment.



Heartland Collaborative demonstrated a **22%** decrease in Medical Home activities in Year 3.

Medical home activites was not one of the primary prioriities in FY2014.

Dissemination Activities

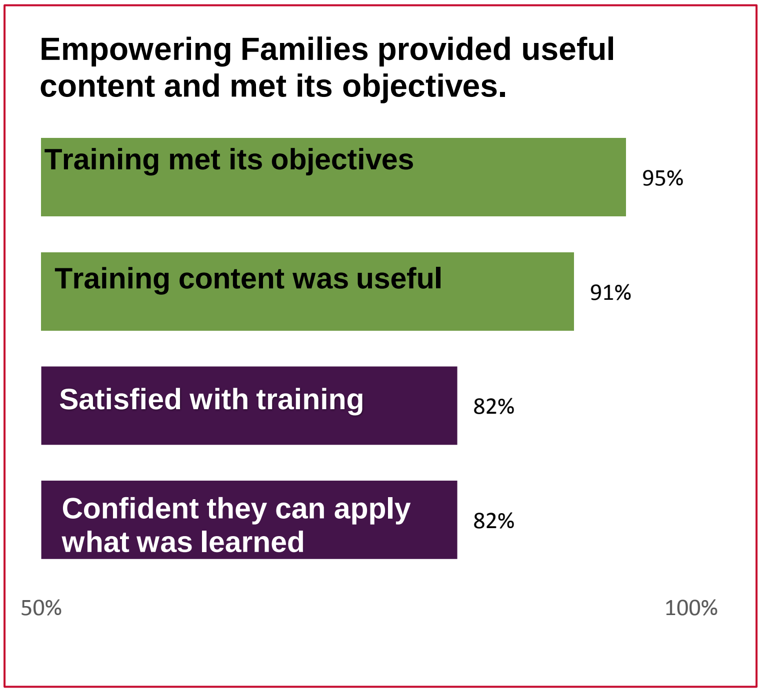
A concept paper from the Medical Home Workgroup of the Heartland Genetics Services Collaborative was completed this grant year. Although much has been published about the patient-centered medical home, the role of the medical geneticist within this model of care had not been delineated in the literature. After reviewing the literature, debating practice models, and communicating with colleagues in primary care as well as geneticists across the Heartland region, the ad hoc Heartland Medical Home Work Group documented their position in a paper that is now available on the on Heartland Collaborative website (http://www.heartlandcollaborative.org/role-geneticist-medical-home/and published as a commentary in Genetics in Medicine.

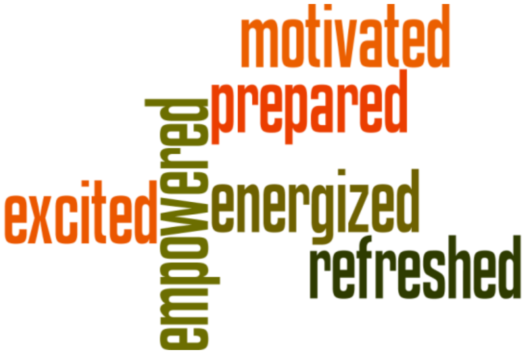
Care Coordination

The *Care Coordination: Empowering Families* training curriculum was developed by the Region 4 Midwest Genetics Collaborative. It was created in partnership with representatives from public health, genetics and primary care providers, parents and consumers of genetics services. They recognized that even when care coordination is provided within a medical home, the role of the family is an important one and there are few opportunities for formal training for parents on managing these tasks. With this information, a training curriculum was created to help parents work collaboratively with their child's physicians and care providers to better meet the needs of the child and family.

The purpose of the training is to provide parents with the skills, knowledge and resources they need to coordinate care for children with complex needs in partnership with a medical home. Heartland partnered with Region 4 Midwest to provide a Care Coordination Facilitator Training in the Heartland region. The 24 individuals who participated were from six different states. One organization sent four participants.

Empowering Families training evaluation included a completion of a post training satisfaction survey, a pre-post knowledge assessment, and a one-word activity in which the participants described the training. The feedback received during and after the training was very positive and met the needs of the participants. Participants stated, "this training is the best one I've attended," "great training," and "thank you for such a great opportunity!" In addition, participants demonstrated an increase in key knowledge in the areas of care coordination, medical home, transition, advocacy, importance of self-care, evaluating resources, and navigating health insurance.





Transition Project

The Center for Disabilities at the University of South Dakota (USD) Sanford School of Medicine has partnered with the Heartland Genetics Services Collaborative to understand and address some of the issues related to developing processes and practices that support successful health care transitions for youth with special health care needs and, specifically, those with genetic conditions. This year was focused on piloting model educational and clinical practices which included the development of tools. A three-day training, "TRANSITIONS of CARE: Moving from Pediatric to Adult Medical Care for Adolescents with Chronic Health Conditions and/or Disabilities," was completed by seven third-year pediatric residents of the Sanford School of Medicine doing their adolescent rotation. This training provided a comprehensive series of didactic and practical experiences that addressed the area of health care transition including current models of practice, pragmatic tools that promote effective transition, and implications for health care to insure quality patient outcomes. In addition to these educational pilots, two clinical pilots were implemented, including a:

- **Transition Consult,** e.g., a 2-hour consultation designed to assess an adolescent's [and their family's] current "status" as it relates to making health care transitions and

- **Transition Clinic,** e.g. a multi-disciplinary, daylong comprehensive clinic that is designed to assess an adolescent's [and their family's] status" as it relates to making health care, education and employment transitions.

How well did you do it? The residents reported that the Transition Engagement Tool was very helpful as they worked with families as part of their training. Preliminary results have found that parents were very satisfied with the clinical pilots.

Was anyone better off? The work with the residency program resulted in refined training and has become a permanent fixture of the pediatric training program at the USD Sanford School of Medicine. The faculty in charge of the residency has elected to continue this training experience and has suggested that it be expanded to family practice residency training. Currently, seven residents gained skills that they can use as they move into their practices. Families who attended the clinics benefited by having a systematic and comprehensive assessment completed with recommended next steps they can take to implement the transition plan for their adolescent child.

Transition Clinics make a difference.

"I hope…that other families will have this wonderful experience….to give another young person the opportunity to use this great resource to assist them as they transition to the adult world. I highly recommend it! A++."
…….Clinic Parent

Two products were the result of the transition product:

1. Transition Engagement Guide: this is a conversation guide for providers to have with youth and their parents.
2. A companion piece to the engagement guide is a tool, with graphic prompts, to guide youth in conversing with their healthcare providers and in self-advocacy.

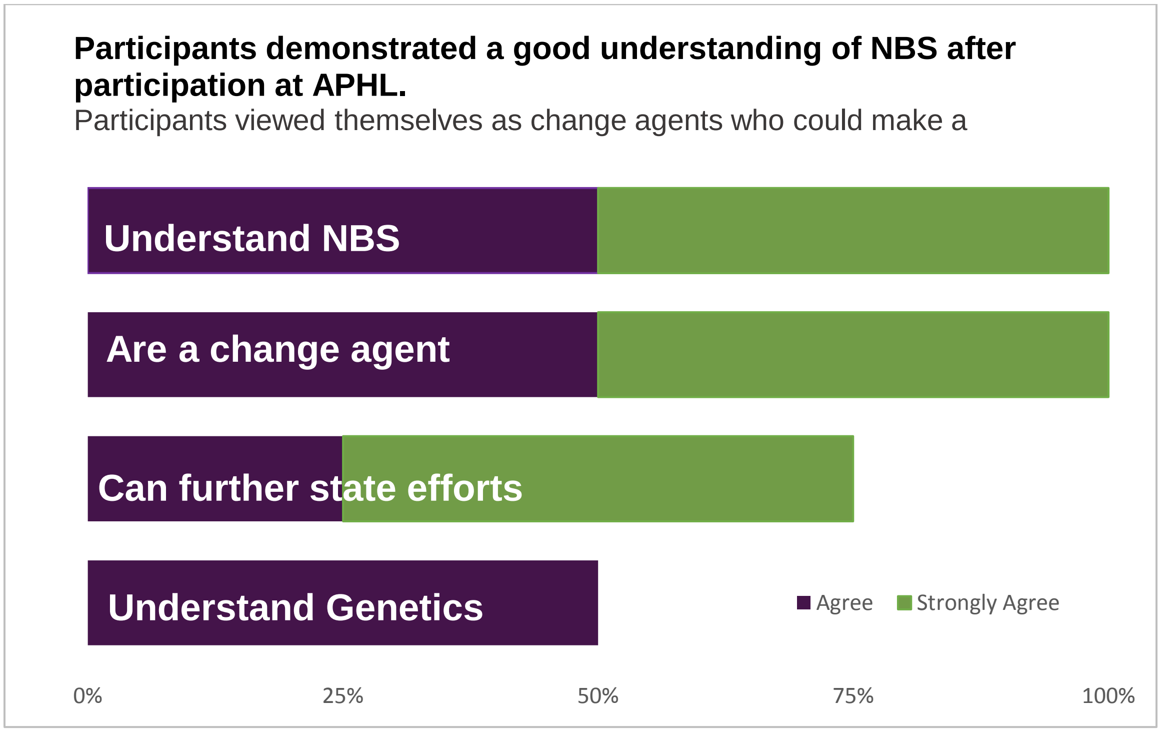
HRSA Priority 3: Expand the pool of the genetics service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties and educators.

Early Hearing Detection and Intervention (EHDI) Program Exchange

The EHDI Program Exchange was previously implemented by the EHDI coordinator visiting another state program to learn from their EHDI processes. This year a modification to the approach was made that included an interactive workshop. A national consultant, Dr. Karl White, the Director of the National Center for Hearing Assessment and Management, participated in the workshop. The workshop was structured so there was time for a networking exchange among the participants. Six EHDI coordinators identified targeted objectives for discussion at the networking section as the workshop was based on a self-assessment process. This information also served as the pre-assessment for the exchange activity. In six months, a follow-up rating will be completed to determine the degree that the program participants incorporated the new strategies into their practices or other system changes that resulted from information gathered from the workshop and the networking exchange sessions. A sample of the content from these identified objectives included: how to better interface follow-up with Early Head Start or Early Intervention programs; how best to address "state border" infants; strategies to increase communication with primary care physicians; strategies to improve follow-up with home-birth populations; exploration of parent liaisons to support other parents through the process; and exploration whether other states are beginning to test for CMV. Six states (i.e., Iowa, Missouri, North Dakota, South Dakota, Kansas, and Nebraska) participated in the interactive workshop. Overall, the participants indicated that having an interactive workshop with content targeted specifically for their group was very valuable. They appreciated the willingness of the Heartland Collaborative to sponsor this and to support their travel expenses to attend.

Collaborative Partners Program (CPP)

In 2014, five states participated in a Heartland Collaborative Partners Program (CPP). This project recruited participants from the eight heartland states. The participants selected were interested in learning more about newborn screening (NBS) and perceived themselves as change agents who can work in their state to make a difference.

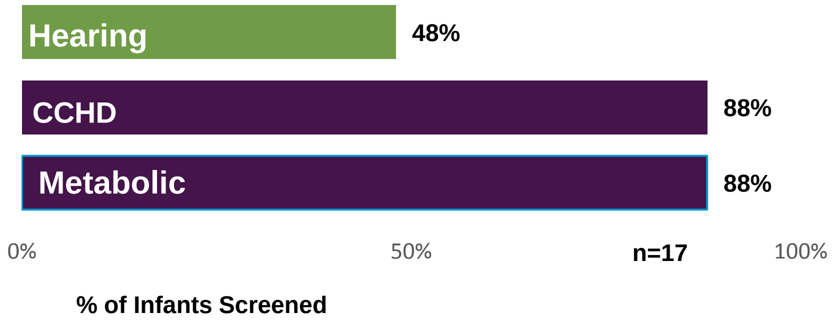


Project Outcomes

Each participant completed their proposed plan, and the results of that implementation were summarized based on their own evaluation strategies as well as through an interview with the evaluator. Three primary strategies were adopted including: needs assessment, promotion of policy change, and training. The majority of the state partners in their project targeted the dissemination of information through articles and training/education activities as their primary strategy for change.

Midwives Needs Assessment. Oklahoma and Missouri both implemented activities to find additional ways that midwives could increase their knowledge of and involvement in NBS. Missouri completed a needs assessment survey with 17 midwives. The majority (71%) of the midwives delivered 26 or more births per year. Critical congenital heart disease (CCHD) and metabolic screening were being completed on the majority of the infants who were delivered at home.

The majority of infants delivered by midwives receive CCHD and Metabolic Screening.
Cost, access to equipment, and parent refusals were the primary barriers to screening.



Oklahoma had passed legislation in 2013 that required a pulse oximetry screen on all babies to identify newborns who are at risk for critical congenital heart disease. Home births were excluded from this mandate. There was growing interest among midwives in Oklahoma to start offering a pulse oximetry screen. Midwives identified the need for further education (e. g., implementation process, interpreting the results, and follow-up recommendations) in the area of pulse oximetry. This project developed a Task Force to create procedures related to pulse oximetry screening for home births, the referral process for newborns, and training and outreach to midwives on these procedures. Training was provided to 12 providers (e. g., midwives, students and midwife assistants). Results of a pre-post test found that the majority of the participants answered 75% or more of the items correctly, suggesting change in knowledge of those who participated.

All participants agreed (66%) or strongly agreed (34%) that **oximetry screen** should be **delivered outside of clinical settings**.

80% of the participants indicated that they would **purchase the equipment** to perform the pulse oximetry screen.

Policy. Nebraska chose to complete a policy statement for their project. In the Spring of 2015, the community partner and state coordinator completed a policy statement, *2015 The State of Nebraska's Newborn Screening Program and Resource Needs in Today's Evolving World*. This Policy Statement was completed to emphasize the importance of Nebraska adopting new conditions that were endorsed by the Secretary on the Recommended Universal Screening Panel. In order for Nebraska to add any new test, additional funding and personnel are needed. In addition, funding increases will be essential to ensure continued access to the medically necessary metabolic foods and formula that ensure continued successful outcomes for individuals with metabolic disorders identified through newborn screening. The paper included specific recommendations that were provided to the Chief Medical Officer for consideration for action.

Training. In Arkansas, there was a need to train current and new providers (physicians, nurse practitioners, and office nurses) to increase their awareness on what to do with positive screens and the importance of follow-up on failed NBS condition screens. A total of nine providers completed the training and the post assessment. The results of the assessment found that 78% of the participants gained knowledge from their participation in the workshop (scored 80% or higher).

The majority of the state partners targeted dissemination of information through articles and education activities as their strategy for change.

Partners Next Steps to Action	States				
	AK	IA	MO	NE	OK
Dissemination of NBS information through **education opportunities and articles.**	■	■	■		
Development of Condition-Related **Action Plans**		■			
Policy Position Paper to Increase Infrastructure Supports and Services				■	
Linkages between state NBS program and **Midwives Association**			■		
Establishment of **quality improvement process** to improve NBS process					■

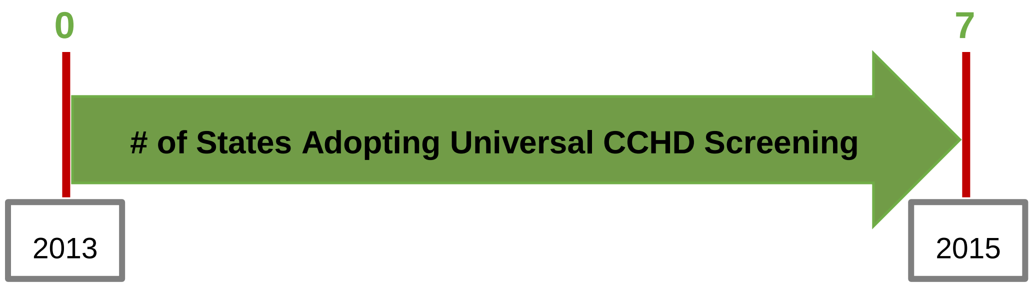
HRSA Priority 4: Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services.

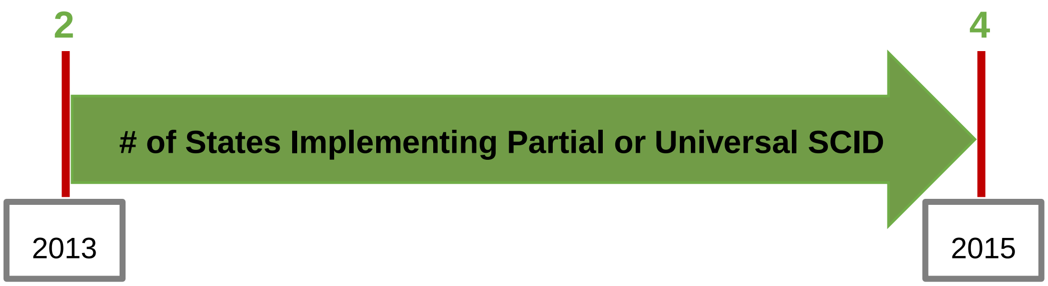
Critical Congenital Heart Defect (CCHD) and Severe Combined Immunodeficiency (SCID) Screening for Newborns

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 was posted on the Heartland Collaborative website: http://www.heartlandcollaborative.org/scidtoolkit. The majority of the states (7 out of 8) in the region have adopted universal CCHD screening. The one state that does not have a mandate, reported that almost 100% of the facilities are screening for CCHD. Slower progress was being made on the adoption of SCID. Only four states were implementing universal levels of screening for SCID.

Majority of states have adopted universal CCHD screening.

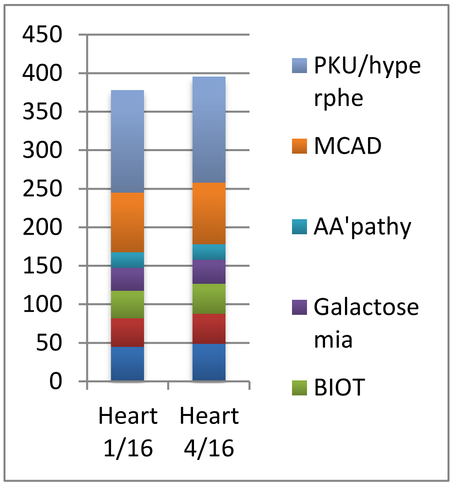
50% of the states are implementing (partial or universal) screening of SCID.





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.

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 (398) through April 2016. The majority of the patients were diagnosed with PKU (31%) 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

In 2014, the Genetic Services Assessment (GSA) project completed the metrics development process with the main deliverable, the GSA tool version 2.0, and began dissemination to two additional regions. The tool was implemented in both the Mountain States Collaborative and the New York and Mid-Atlantic Collaborative (NYMAC). We held an initial meeting with both collaboratives and a series of webinars to discuss the logistics of the implementation process. The tool was distributed to individual states for completion over a three-month period. The Mountain States had a 50% response rate while the NYMAC region had a 75% response rate. Both regions had similar patterns of strengths and areas that may warrant further exploration for improvement in genetic service delivery. Strengths were in the areas of State Capacity of Services (e.g., availability and early screening and diagnosis), Access (e.g., access to most genetic professionals), and Performance Reporting and Improvement (e.g., security of electronic information and availability of documentation of data sources). Two consistent areas for improvement were noted across regions, including Performance Reporting (e.g., use of documentation of data sources) and Work Force (e.g., workforce training adequacy). Qualitative information was also collected about specific metrics. Each region received an aggregate report and each state received a customized report comparing its performance to the regional aggregate.

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, 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 three states. This process involved the development of a questionnaire, an informed consent information sheet, and a flier to recruit families. Recruitment of families began in April 2014. The following is a description of their preliminary findings. A total of 26 in-person interviews were conducted in Spanish: 8 in Oklahoma, 10 in Nebraska and 8 in Kansas.

How well did Heartland do it? All the interviews have been transcribed into Spanish and are also being analyzed in Spanish in order to maintain the integrity of the data. Both the Oklahoma and Nebraska interviews have gone through the first analysis. Four preliminary themes were identified:

- Variability of translation service, including modality and integrity of the translation.
- Lack of genetic knowledge and understanding of the need for genetic services.
- Families expressing dissatisfaction with services with regard to how the provider treated them, and not the quality of services.
- The critical role of the Hispanic family network coordinators and the bilingual early intervention staff in empowering the families to being proactive in seeking medical and financial services.

Was anyone better off? Based on these preliminary themes, the goal for this grant year is to address the following recommendations:

- the availability of education/information resources to explain genetics services and inheritance in a meaningful way;
- assess the impression of many interviewees who assert that the interpretation services are not always accurately translating the conversation; and

- assess the roles of the health services and family support systems that have the most contact with the Hispanic families

In order to address these recommendations, the regional Hispanic Access Advisory committee will reconvene to allow for the planning and implementation of activities that will lead to increasing access to genetic care for Hispanic families. New members will be added to the committee to include more representation from our current collaborators who have participated in the Hispanic Access Project and serve Hispanic families at community-based clinics and family support networks. In addition, this collaboration has resulted in the integration of Spanish-speaking professionals in the RC as members of the advocate work group. Their involvement will facilitate future outreach activities in Hispanic communities across the Heartland region.

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. 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. Heartland posted material on its website regarding each of these key areas.

Home page visits were consistent with the previous year. The number of unique visits doubled compared to the previous year. Heartland Collaborative's website had:

3093 unique visits

4555 home page visits.

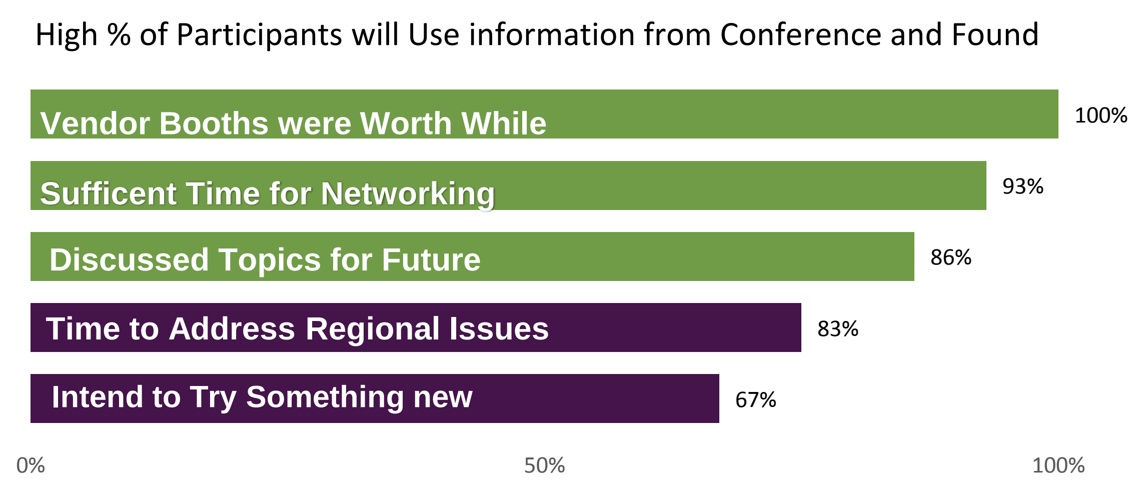
2356 page views

119 YouTube visits

Two key Heartland-developed resources are available for download on the Heartland website. Both had multiple downloads: Heartland Family Toolkit (35) and Care Coordination Partnership Guide (28). Heartland Genetics provides recorded webinars on a variety of genetic-related topics for a broad spectrum of stakeholders. Heartland Genetics will add additional videos as they become available. The link is: https://www.youtube.com/user/HeartlandGenetics. The reference is: Schaefer GB, Larson IA, Bolick J, and Williamson-Dean L. "What is the role of clinical genetics in the patient-centered medical home?: A commentary from the Medical Home Workgroup of the Heartland Regional Genetics and Newborn Screening Collaborative": *Genetics in Medicine* 2015; published online 20 August.

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. 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 Heartland Conference was rated positively. Overall, the ratings and comments suggest that the conference was very beneficial for participants.

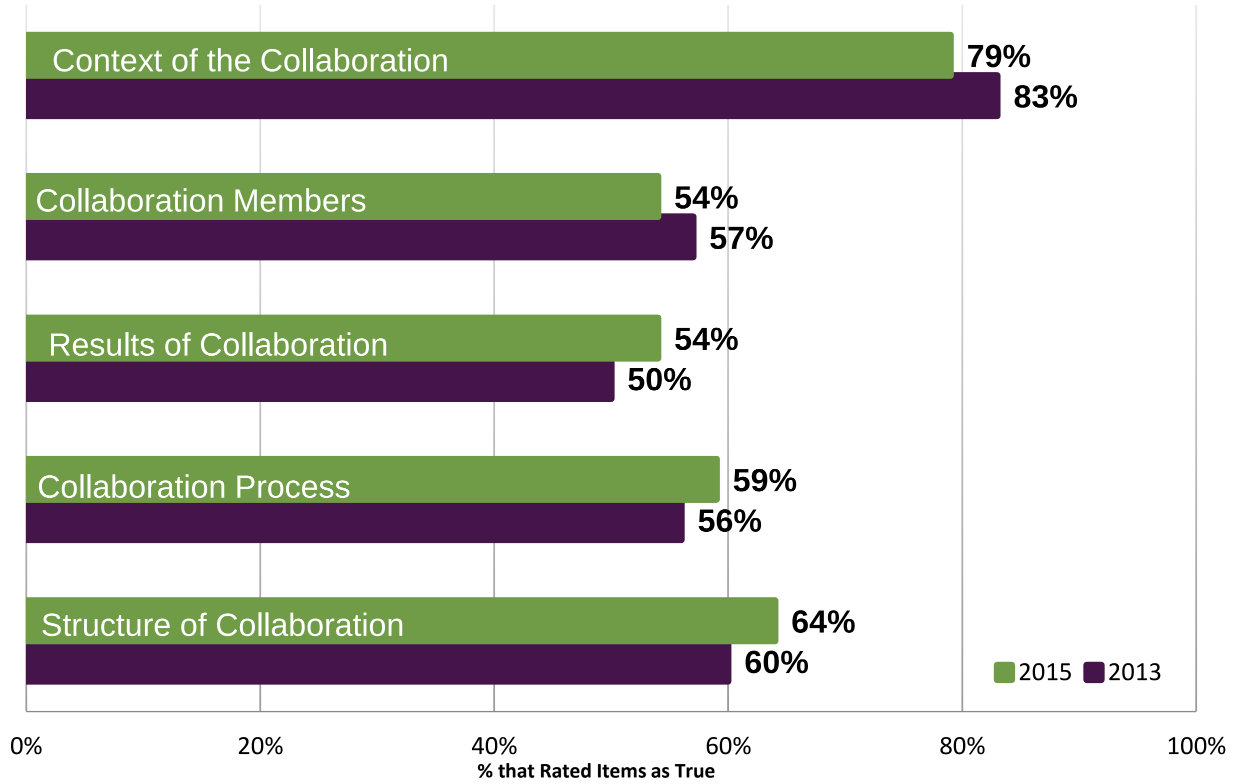


Working Together: Evaluation of the Heartland Collaboration

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). This assessment was completed as part of the national evaluation. Members of the Heartland Collaborative were asked to rate the 40 items based on a four point Likert scale (1=False and 4= True). The first administration through SurveyMonkey^{TM} was completed for the 2013 national evaluation and was re-administered in 2015. In 2013, Heartland distributed to a small cross-sample of its membership (n=15). In 2015 the distribution was expanded to include all members of the advisory board and workgroups (n=91). A total of 55 individuals participated for a response rate of 60%. A large majority (62%) of the respondents had participated in the Heartland for over three years. Most of the respondents participated in the annual meeting (69%) and/or work groups (79%). For this report the percentage who rated the items as “true” were reported.

Heartland Collaborative members reported increased collaboration in the areas of its Structure, the Process and the Results since 2013.

Fewer members rated the Context and Members as high in collaboration in 2015.



Results of this survey will inform the overall needs assessment process being conducted in 2015-2016.

Summary of Collaborative Strengths and Areas Targeted for Improvement

CONTEXT	The results of the survey demonstrated that the timing was right to address NBS and genetic issues (87%) and that Heartland Collaborative was responding to these critical issues (67%).
MEMBERS	Although member collaboration was rated somewhat lower than in 2013, there were several strengths in this area. Members reported they trusted each other to honestly and accurately share information and feedback (71%) and balanced tasks and social needs so that the group could work comfortably and productively (71%). The lowest rated area was the willingness of members to devote the effort necessary to achieve the Heartland Collaborative goals. This lower rating is not surprising, given that that majority of the membership is comprised of volunteers who have full time positions in state agencies or community organizations or are family members or consumers.
RESULTS	Although improved from 2013, results were the lowest rated area of the five components of collaboration. Strengths were in Heartland Colllaborative's effort directed at obtaining its goals (72%), although fewer (44%) reported that there was a method of monitoring performance and providing feedback on goal attainment. The group did report that it was willing to confront and resolve performance issues (62%).
PROCESS	The leadership of the Heartland Collaborative was rated positively (75%). It was reported that there was open communication as divergent opinions were expressed and listened to, as well as a strong concern for preserving a credible and open process (71%). There was less opportunity to discuss how the Collaborative was working together (39%).
STRUCTURE	The structure of the Collaborative was one of the highest rated areas. The members had access to expertise necessary for effective meetings (83%). Communication processes and workgroup structures were also viewed positively (72% for both). Clearly defining roles for group members was an area that could be targeted for improvement (43%).

Summary of Heartland Collaborative Data for National Common Measures - YEAR 3

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 monthly phone conference meetings to support the implementation of the national evaluation plan. A summary of these findings on the national measures can be found in the following tables.

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

The majority of participants in the Heartland Collaborative and across regions were providers.

	PROVIDERS	CONSUMERS	FAMILY ORGANIZATIONS	DISEASE-SPECIFIC or ADVOCACY ORGANIZATIONS
# on RC mailing list	**Heartland %: 87%**	**10%**	**1.5%**	**1.5%**
	Heartland: 100	**11**	**2**	**2**
	All Regions: 3582 82%	372 9%	153 4%	245 5%
PARTICIPANTS IN RC ACTIVITIES				
# who attended RC annual meeting	**Heartland %:** **85%**	**7%**	**6%**	**2%**
	Heartland: 72	**6**	**5**	**2**
# who participate on RC workgroups	**Heartland %: 81%**	**17%**	**2%**	
	Heartland: 51	**11**	**1**	**0**

Heartland used a variety of strategies to train participants in the region.
The highest percentage of participants engaged in in-person meetings.

HRSA Priorities	In-person meetings	In-person participants	Webinars	Webinar participants	Teleconferences	Teleconference participants
1. Treat in the context of a medical home	1	144	4	50	1	9
2. Reach cultural competency and diversity in outreach projects	2	130	2	25	22	90
3. Expand the pool of the genetic service workforce	1	12			3	30
4. Build state public health department capacity	1	40	2	45	7	154
5. Strengthen public-private partnerships	1	10			6	48
6. Collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices						
7. Improve insurance coverage policy and reimbursement – Affordable Care Act Implementation						
8. Expand state/ regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.	1	91				
9. Address emergency preparedness	1	40	2	45	7	154
Others not in RFA – Transition from Pediatric to Adult Care					1	14
Telemed	1	14			2	
Communicating with Families	1	91				
TOTAL sessions/participants	10	572	10	165	49	499

<table>
<tr><td colspan="7">Heartland Collaborative has an active website that provides information across HRSA priority areas.</td></tr>
<tr><td colspan="7">Home page visits Total : 4,555
(Using Google Analytics)</td></tr>
<tr><td colspan="7">Unique visits Total : 3,093
(Using Google Analytics)</td></tr>
<tr><td></td><td>Medical Home</td><td>Newborn Screening Capacity Building</td><td>Collaborations</td><td>Affordable Care Act Implementation</td><td>Newborn Screening Long Term Follow up</td><td>Transition from pediatric to adult care</td></tr>
<tr><td>RC website has pages that address these topics (Y/N)</td><td>Y</td><td>Y</td><td>Y</td><td>Y</td><td>Y</td><td>Y</td></tr>
<tr><td colspan="7">SOCIAL MEDIA</td></tr>
<tr><td>RC uses Social Media (Y/N)</td><td colspan="6"></td></tr>
<tr><td>If yes, please indicate type AND Number Of unique followers as of May 31, 2015:</td><td colspan="6">FACEBOOK: _119____
TWITTER: ____NA___
PINTEREST: ___NA__
OTHER: _YouTube: Heartland Genetics provides recorded webinars on a variety of genetic-related topics for a broad spectrum of stakeholders. Heartland Genetics will add additional videos as they become available; the link is: https://www.youtube.com/user/HeartlandGenetics</td></tr>
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Heartland Collaborative Engagement in Medical Home Activities

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**				
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				

Heartland Collaborative Engagement in Medical Home Activities

0	1	2	3	Element
	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_____				

Heartland Collaborative is actively addressing 6 of the 9 HRSA priorities.	
HRSA Priorities	Insert an X for RC activities that address the priority area
1. Treat in the context of a medical home	**X**
2. Reach cultural competency and diversity in outreach projects	**X**
3. Expand the pool of the genetic service workforce	**X**
4. Build state public health department capacity	**X**
5. Strengthen public-private partnerships	
6. Collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices	
7. Improve insurance coverage policy and reimbursement	
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.	**X**
9. Address emergency preparedness	**X**
Others not in RFA – Transition/ Genetics Systems Assessment; Telemed	**X**

Heartland Collaborative participated in a variety of intra- and inter-regional activities, demonstrating the value of a regional approach.	
Intra-Regional (within a region)	Inter-Regional (between RCs)
Medical Home	
	Title: Care Coordination Training / Empowering Families Training **Description**: Provided the Care Coordination Training (train the trainer) in the Heartland region. Eleven organizations from six of the Heartland's eight states totaling 24 participants were trained. These organizations must conduct a parent training by November 1, 2015. **Who with**: Heartland and Region 4 **Accomplishments**: Increased dissemination of the curriculum.
Long-term Follow-up	
:	**Title:** IBEM-IS **Description:** 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. **Who with**: Heartland and Region 4 **Accomplishments**: Participation in these pilots will help to facilitate the states adoption of case definitions for the recommended uniform screening panel.
Telegenetics	
	Title: Telegenetics **Description**: Educated genetics residents, genetic counseling students and those in practice less than five years in partnership with Western States region.

Heartland Collaborative participated in a variety of intra- and inter-regional activities, demonstrating the value of a regional approach.	
Intra-Regional (within a region)	Inter-Regional (between RCs)
	Who with: Heartland and Western States **Accomplishments**: 13 trainees (2 medical genetics residents, 1 medical geneticist, 9 genetic counselors, and 1 clinic coordinator).
Other	
	Title: Genetic Services Assessment (GSA) Project **Description**: The Genetic Services Assessment (GSA) is a tool developed for state level public health programs to use in assessing the genetics systems/services in their respective states. **Who with**: NYMAC and Mountain States **Accomplishments**: 9 states completed the tool bringing the total number of states that have implemented the tool (past versions and current version) to 20. NYMAC states used the tool to assist Title V programs in current needs assessment and planning activities for the next five years.

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

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