

# HEARTLAND GENETICS & NEWBORN SCREENING COLLABORATIVE

Evaluation Plan  
2009-2010



[www.heartlandcollaborative.org](http://www.heartlandcollaborative.org)

## **Evaluation Process**

The comprehensive evaluation for the Heartland Genetics and Newborn Screening Collaborative (Heartland) includes collecting data to monitor Heartland's implementation and identified program outcomes, as well as the federally mandated HRSA common outcome performance measures. This program evaluation is a dynamic process that utilizes a multi-method approach, including qualitative and quantitative methodologies and that will encompass formative and outcome evaluation, based on the logic model theory of change.

The project manager and evaluation consultant are responsible for the development and implementation of the evaluation plan and the data analysis. The following tables describe the three major components of this project's evaluation including: 1) evaluation of the implementation and utilization of services; 2) outcome-based evaluation using qualitative and quantitative data, and 3) the HRSA common outcome performance measures. This information is used to verify achievement of project outcomes and objectives and its impact on participants. Built into the evaluation process is ongoing review of formative and summative data to inform program improvement through reflection and action planning. The continuous improvement process for the Heartland includes providing ongoing information which assists Heartland Regional Coordinating Center staff, the Heartland Advisory Board, and state partners to improve their leadership efforts, state NBS systems and local projects.

The following tables provide information on the activities, evaluation strategies, and outcomes measures for the Heartland project's four identified goals and federal performance measures.

Heartland Genetics and Newborn Screening Collaborative  
Evaluation Plan – 2009 - 2010

Goals	Strategies	Implementation Evaluation Measures	Outcome Evaluation Questions	Outcome Evaluation Measures	Outcome Data Collection Timeline <sup>1</sup>
<b><u>Clinical Genetic Services</u></b>  1) Facilitate access to quality clinical genetic services	<ul style="list-style-type: none"> <li>Collaborate with Region 4 on Laboratory Performance project</li> </ul>	<ul style="list-style-type: none"> <li>Document # of states who contribute data to the project</li> </ul>			<ul style="list-style-type: none"> <li>Ongoing</li> </ul>
	<ul style="list-style-type: none"> <li>Collaborate with Region 4 on IBEM-IS project</li> </ul>	<ul style="list-style-type: none"> <li>Document participation in the study and # of data entries reimbursed</li> </ul>			<ul style="list-style-type: none"> <li>Ongoing</li> </ul>
	<ul style="list-style-type: none"> <li>Promote use of telehealth strategies for clinical genetics</li> <li>Implement metabolic rounds using telehealth technology</li> <li></li> </ul>	<ul style="list-style-type: none"> <li>Document states use of telehealth clinical genetics</li> <li>Document participants attending rounds and describe their characteristics</li> </ul>	<ul style="list-style-type: none"> <li>Does the information support providers in the treatment and management of clients in their practice?</li> <li>To what extent does it increase knowledge of state resources?</li> <li>Do new inter-state systems collaborations result from participation?</li> </ul>	<ul style="list-style-type: none"> <li>Survey of participants who participate in forums</li> </ul>	<ul style="list-style-type: none"> <li>Ongoing</li> <li>Year 6 and 7</li> </ul>
<b><u>Genetics Education</u></b>  2) Promote genetics education	<ul style="list-style-type: none"> <li>Partner with Utah MedHome Portal to strengthen medical home through education of primary care providers via web-based modules</li> <li>Establish continuing education credits (CME) and assessment requirements and identify demographic data for future evaluation analyses</li> </ul>	<ul style="list-style-type: none"> <li>Document completion of seven diagnosis modules</li> <li>Document # of providers that complete modules (CME)</li> <li>Describe characteristics of providers that completed the modules</li> </ul>	<ul style="list-style-type: none"> <li>To what extent do the providers find the content and format of the modules helpful?</li> <li>What percentage of providers who complete the knowledge assessment meet the set criteria?</li> </ul>	<ul style="list-style-type: none"> <li>Satisfaction survey tool completed by providers who finish modules</li> <li>Completion of module knowledge assessments</li> </ul>	<ul style="list-style-type: none"> <li>Beginning Year 6</li> <li>Beginning Year 6</li> </ul>

<sup>1</sup> Year 6 is 06/01/2009 through 05/31/2010  
Year 7 is 06/01/2010 through 05/31/2011

Goals	Strategies	Implementation Evaluation Measures	Outcome Evaluation Questions	Outcome Evaluation Measures	Outcome Data Collection Timeline <sup>1</sup>
2) Promote genetics education (continued)	<ul style="list-style-type: none"> <li>Identify strategies to promote 6 regional LEND programs awareness of Heartland</li> <li>Partner with LENDs to evaluate the potential use of Diagnosis Modules as a training option for LEND Trainees</li> <li>Investigate potential of presenting at Midwest LEND meeting in Fall 2009</li> </ul>	<ul style="list-style-type: none"> <li>Document awareness strategies to promote Heartland with LEND network</li> <li>Document faculty and students who participated in collaborative project and determine from them usefulness of modules</li> </ul>	<ul style="list-style-type: none"> <li>To what extent is the work between Heartland and LEND programs collaborative?</li> <li>To what extent are the diagnosis modules a useful educational tool for LEND students?</li> </ul>	<ul style="list-style-type: none"> <li>Interviews of key stakeholders from both programs</li> <li>Completion of module ratings by LEND faculty and students</li> </ul>	<ul style="list-style-type: none"> <li>Year 6</li> <li>Year 6</li> </ul>
	<ul style="list-style-type: none"> <li>Develop and disseminate a Family Financial Resource Guide</li> </ul>	<ul style="list-style-type: none"> <li>Document completion of the Guide</li> <li>Document dissemination of the guide to stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>To what extent are the genetic nurses and counselors using the Family Financial Resource Guide with families</li> </ul>	<ul style="list-style-type: none"> <li>Survey of genetic nurses and counselors on the utility of the Financial Resource Guide</li> </ul>	<ul style="list-style-type: none"> <li>Year 7</li> </ul>
	<ul style="list-style-type: none"> <li>Create a partnership with the University of Iowa to allow for nurses to have access to University online genetic modules</li> </ul>	<ul style="list-style-type: none"> <li>Document partnership agreement with University of Iowa</li> <li>Document number and characteristics of the nurses who enroll in the online genetic modules</li> </ul>	<ul style="list-style-type: none"> <li>To what extent do nurses in the region complete the online genetics course?</li> </ul>	<ul style="list-style-type: none"> <li>Number of courses passed by enrolled nurses</li> </ul>	<ul style="list-style-type: none"> <li>Year 6</li> </ul>
<b><u>Infrastructure Support</u></b> 3) Infrastructure to facilitate networking	<ul style="list-style-type: none"> <li>Genetics System Assessment (GSA) tool developed</li> <li>GSA tool piloted in two states</li> <li>GSA implemented in eight states to determine the quality of their genetics service system</li> </ul>	<ul style="list-style-type: none"> <li>GSA tool is established based on scientific approach</li> <li>GSA tool is modified based on feedback from pilot</li> <li>Document evidence review and Delphi and pilot experiences in a manuscript</li> <li>Eight Heartland states complete GSA</li> </ul>	<ul style="list-style-type: none"> <li>To what extent was the GSA a helpful approach to assessing a quality system?</li> <li>To what extent do states in the Heartland have quality systems of care?</li> </ul>	<ul style="list-style-type: none"> <li>Survey tool completed by pilot sites</li> <li>Completion of GSA in eight states</li> </ul>	<ul style="list-style-type: none"> <li>Year 6</li> <li>Year 6-7</li> </ul>
	<ul style="list-style-type: none"> <li>Newborn screening state programs identify a partner for a NBS program exchange and implement a site visit</li> <li>Agenda for the site visit is submitted and approved by Heartland</li> </ul>	<ul style="list-style-type: none"> <li>Site visit is completed</li> </ul>	<ul style="list-style-type: none"> <li>To what extent did the site visit contribute to adoption of or modification of a clinical practice or system procedure?</li> </ul>	<ul style="list-style-type: none"> <li>Pre-post analysis of PEAS (post test at 12-month follow-up)</li> <li>Interviews of stakeholders</li> </ul>	<ul style="list-style-type: none"> <li>Years 6 - 7</li> </ul>

Goals	Strategies	Implementation Evaluation Measures	Outcome Evaluation Questions	Outcome Evaluation Measures	Outcome Data Collection Timeline <sup>1</sup>
	<ul style="list-style-type: none"> <li>• The Heartland NBS Back-up Testing and Quality Assurance Project complete drills with 2-3 states, implementing back-up system</li> <li>• Implement one NBS workshop per year related to NBS back-up project process and regional laboratory harmonization</li> <li>• Establish links with FEMA and HSEEP regarding NBS Back-up Project</li> </ul>	<ul style="list-style-type: none"> <li>• Document completion of NBS Back-up project drill</li> <li>• Document protocol and process of the EMAC procedures in a manuscript</li> <li>• Document the # of states that could implement NBS Back-up project protocol</li> <li>• Document contacts with FEMA and HSEEP</li> </ul>	<ul style="list-style-type: none"> <li>• How effective was the implementation of the back-up system?</li> <li>• To what extent was the workshop effective?</li> </ul>	<ul style="list-style-type: none"> <li>• Data from the NBS Back-up project sites with comparative analysis of results from two sites</li> <li>• Completion survey evaluating effectiveness of the workshop.</li> </ul>	<ul style="list-style-type: none"> <li>• Year 7</li> </ul>
	<ul style="list-style-type: none"> <li>• Heartland provides resources on website related to youth transition</li> <li>• Heartland sponsors speakers to increase network knowledge on youth transition</li> <li>• Heartland links state participants who are interested in addressing youth transition issues</li> </ul>	<ul style="list-style-type: none"> <li>• Document # of posted resources on website</li> <li>• Document # of awareness activities, including # of states and participants impacted</li> </ul>			<ul style="list-style-type: none"> <li>• Ongoing</li> </ul>
	<ul style="list-style-type: none"> <li>• Sarah Lawrence Scholarship is granted for one student per year to obtain a Public Health Genomics Certificate</li> </ul>	<ul style="list-style-type: none"> <li>• Document selection of scholarship recipient and completion of course</li> <li>• Document presentation of Capstone project at annual conference</li> </ul>	<ul style="list-style-type: none"> <li>• To what extent did completion of the certificate help the participant contribute to the field?</li> </ul>	<ul style="list-style-type: none"> <li>• Interview with participants at course completion and one year post course completion</li> </ul>	<ul style="list-style-type: none"> <li>• Ongoing</li> </ul>
<p><b><u>Leadership Strategies</u></b></p> <p>4) Provide leadership to facilitate activities to promote access to quality clinical genetic programs</p>	<ul style="list-style-type: none"> <li>• Revise and submit strategic plan</li> <li>• Disseminate educational resources using multiple strategies (i.e., website, e-newsletter, list serves, meetings, conferences)</li> <li>• Contact Primary Care Associations and Primary Care Offices (PCA/PCO) in Heartland Region to determine interest in being added to e-newsletter mailing list</li> </ul>	<ul style="list-style-type: none"> <li>• Document submission of plan</li> <li>• Document type and # of participants per strategy</li> <li>• Post minutes of meetings</li> <li>• Document conference schedules</li> <li>• Document e-newsletter mailing list subscribers</li> </ul>	<ul style="list-style-type: none"> <li>• To what extent do the leadership activities reflect the priorities and needs of the Heartland Collaborative?</li> <li>• What are the contributing and inhibitory factors that influence the success of the Heartland Collaborative?</li> <li>• To what extent have the Heartland Advisory Board and Work Groups formed a collaborative partnership?</li> </ul>	<ul style="list-style-type: none"> <li>• Focus group</li> <li>• Satisfaction survey on group meetings</li> <li>• Measure of collaborations (i.e., Working Together, Tent exercise)</li> </ul>	<ul style="list-style-type: none"> <li>• Year 7</li> <li>• Ongoing</li> <li>• Year 6</li> </ul>

HSRA Common Outcome Measures with Links to the Heartland Evaluation Plan--January 2009

Domain	Outcome	Data Measure	Related Heartland Goal
<b>A. Improved care coordination for people with heritable disorders.</b>	Increase in the percentage of states in the region with collaborations facilitated by the regional collaborative between PCPs and specialty providers to improve care coordination for people with heritable disorders.	<ul style="list-style-type: none"> <li>• # of States in the region</li> <li>• # of states with collaborations facilitated by regional collaborative between PCPs and specialty</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 1: Clinical Service</li> </ul>
<b>B. Improved access to genetic services for people with heritable disorders.</b>	Increase in the # of genetic services visits provided to people with or at risk for heritable disorders through distance strategies implemented by the regional collaborative.	<ul style="list-style-type: none"> <li>• # of genetic service visits provided to people with or at risk for heritable disorders</li> <li>• Types of distance strategies employed</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 1: Clinical Service</li> </ul>
<b>C. Development of regional emergency backup systems for NBS and genetic services.</b>	Increase the % of states in the region that have received current materials or other assistance from the RFC on developing back-up systems for NBS and genetic services.	<ul style="list-style-type: none"> <li>• # of state in region that received current materials or other assistance from the RC on developing back-up systems for NBS and genetic services</li> <li>• List materials or assistance provided</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 3: Infrastructure</li> </ul>
<b>D. Implementation of expanded NBS.</b>	Increase in the % of states in the region that have evaluated and made recommendations on implementing the ACHDGNC (Advisory Committee on Heritable Disorders on Newborns and Children).	<ul style="list-style-type: none"> <li>• # of states that evaluated and made recommendation on implementing the ACHDNC recommended NBS panel</li> <li>• List of states that implemented recommendations</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 3: Infrastructure</li> </ul>
<b>E. Improved follow-up of children identified with heritable disorders through NBS.</b>	Increase the # of NBS follow-up specialty visits provided to families through distance strategies implemented by regional collaborative.	<ul style="list-style-type: none"> <li>• # of follow-up specialty visits provide to families through distance strategies</li> <li>• Type of distance strategies employed # of visits per strategy</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 1: Clinical Service</li> </ul>
<b>E2.</b>	Increased in % of state with systems in place to track entry into clinical management for newborns who are diagnosed with <u>conditions mandated</u> by their State sponsored NBS.	<ul style="list-style-type: none"> <li>• # of states with systems in place to track newborns who are diagnosed with conditions mandated by their State</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 3: Infrastructure</li> </ul>
<b>E3.</b>	Increase in the % in place to track <u>hearing loss</u>	<ul style="list-style-type: none"> <li>• # of states with systems to track hearing loss</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 3: Infrastructure</li> </ul>
<b>E4.</b>	Increase the % children who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening program and/or hearing loss through their State-sponsored newborn hearing screening programs.	<ul style="list-style-type: none"> <li>• # of states with systems in place to track receipt of clinical services and outcomes.</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 1: Clinical Service</li> </ul>
<b>F1. Improved/expanded education of PCPs about treatment of people with heritable disorders and about clinical genetic resources in region</b>	Increase in the % of states in region whose NBS programs disseminate “just-in-time/point-of-care” information on specific heritable disorders to PCPS	<ul style="list-style-type: none"> <li>• # of states whose NBS disseminate information to PCPs</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 2: Promote genetics education</li> </ul>
<b>G1. Improved regional planning around delivery of genetic services to people with heritable disorders.</b>	Completion of regional genetic services plan	<ul style="list-style-type: none"> <li>• Document if regional genetic services plan is completed</li> </ul>	<ul style="list-style-type: none"> <li>• Goal 4: Leadership strategies</li> </ul>

