

HEARTLAND GENETICS & NEWBORN SCREENING COLLABORATIVE

Strategic Plan
2006-2012



www.heartlandcollaborative.org

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Heartland Regional Council on Genetics

Heartland Executive Committee

Support

The Heartland Genetics and Newborn Screening Collaborative thanks the Health Resources and Services Administration (HRSA)- Maternal and Child Health Bureau (MCHB)-Genetic Services Branch for funding the work of this collaborative through the Heritable Disease Program, Grant U22MC03962 with a cooperative agreement with the University of Oklahoma. Many individuals also donated time and effort.

Our Mission

The Heartland Genetics and Newborn Screening Collaborative includes health professionals and advocates who promote and improve health through quality medical genetics services, clinical laboratory services, professional and public education, genetics research and public policy.

Overview of the Heartland Collaborative

The Genetic Services Branch of the Maternal and Child Health Bureau within the Health Resources Services Administration responded to Section 1109 of the Title XI of the Public Health Service Act by establishing the Heritable Disorders Program. The Program's purpose was to "enhance, improve, or expand the ability of State and local public health agencies to provide screening, counseling or health care services to newborns and children having or at risk for heritable disorders. This Program shall improve the access to newborn screening and genetic services for medically underserved populations and shall enhance such activities as: screening, follow-up services; augmentation of capacity needs: training, education; subspecialty linkage, expansion of long term follow-up activities; strengthening of linkage to medical homes; strengthening of linkage to tertiary care; strengthening of genetic counseling services; and enhancement of communication/education to families and health practitioners and other forms of information sharing." The United States and its territories were divided into regions, and each region submitted a proposal for a coordinating center and ways to address the above issues. A national coordinating center was also selected, which is the American College of Medical Genetics. Funding began in October 2004.

A steering committee, comprised of individuals from all eight states in Region 5, rallied a coordinated response to the request for applications. The University of Oklahoma Health Sciences Center was selected as the Regional Coordinating Center. Upon receipt of funding, an advisory council was formed and the council held its first meeting on February 28, 2005, in St. Louis, Missouri.

At that meeting, members drafted the mission statement and organized five committees: Education, Policy, Research, Clinical Services, and Laboratory Services, and each state presented a poster highlighting their state's assets. Upon that foundation, the Heartland Genetics Advisory Council has evolved into a working network of geneticists, advocates, public health stakeholders, and primary care providers.

A new committee, Newborn Screening, and a subcommittee, Cancer Genetics, were born at the second meeting held in Kansas City, Missouri, in October 2005. The hallmark of the second meeting was the drafting of the regional strategic plan, informed largely by committee-based needs assessments and priorities. Subsequent annual meetings have also been held each September in Omaha (2006), Oklahoma City (2007), and Sioux Falls, SD (2008).

In 2007, the committee structure was replaced by Work Groups. Each Heartland Work Group consists of a Heartland staff facilitator, core members and other members. Members represent all eight Heartland states. These Work Groups meet every 4-6 weeks, usually by teleconference and have at least one face-to-face meeting every year at the annual Heartland Collaborative meeting.

Each work group has its own projects to work on throughout the year and most work is conducted by phone and email.

Current work groups are: Clinical Genetic Services; Education; Newborn Screening; and Advocate. Each work group has a webpage with more information and can be found at www.heartlandcollaborative.org.

At the 2008 meeting, members renewed the original Strategic Plan, 2006-2012, and apart for minor suggestions, endorsed it as still true, relevant and challenging.

From the onset, the Heartland Regional Coordinating Center initiated or facilitated regional communication through a website, list-serve, monthly teleconference meetings, and newsletter. In addition, it has increased collaboration through the Heartland Pilot Project Program, which is a competitive bid, peer-reviewed process for pilot projects responding to national and regional priorities. To date, the pilot project program has funded 13 innovative projects, addressing issues of public and provider education, improving health outcomes, access to genetic services, the Medical Home and improved infrastructure of state public health genetics programs. More information about the Heartland Pilot Project Program can be found at www.heartlandcollaborative.org

The regional collaboratives have become the “public health genetics laboratories” for the nation. The Heartland is an equal partner on the national scene, and the Regional Coordinating Center is only a conduit for the hard work, dedication, insightfulness, and creativity of the Heartland collaborative members.

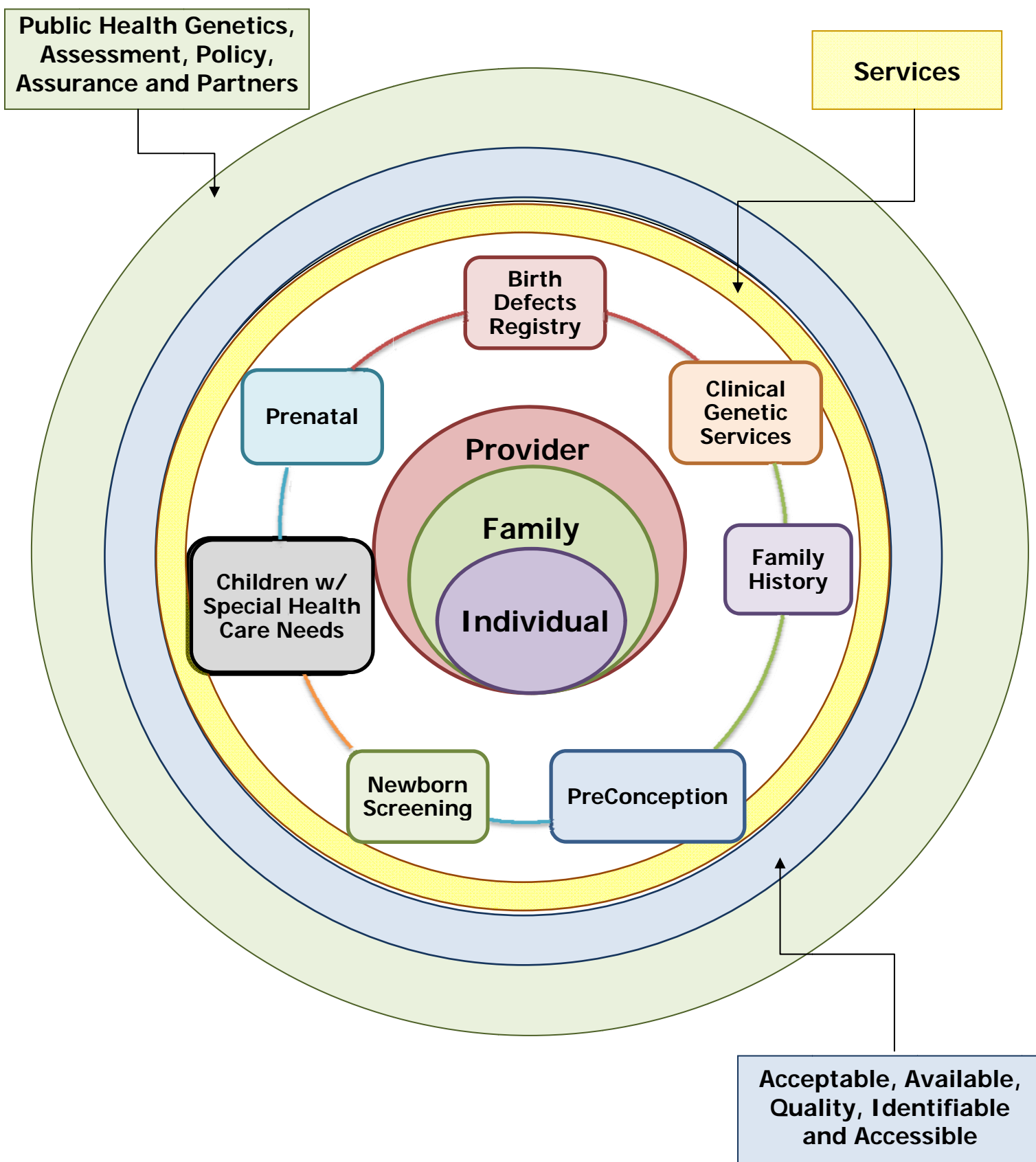
We welcome anyone interested in these issues to join our collaborative.

Most sincerely,

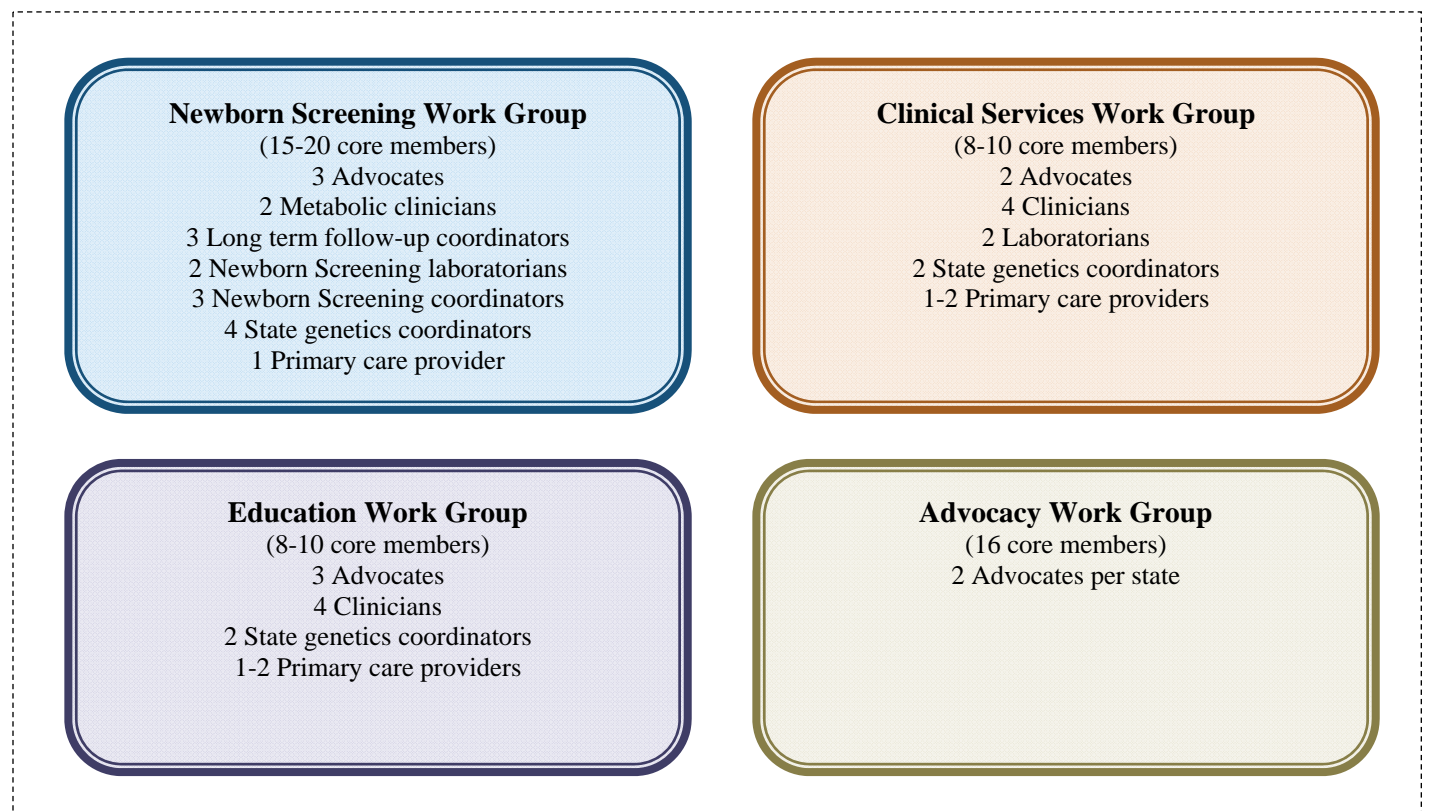
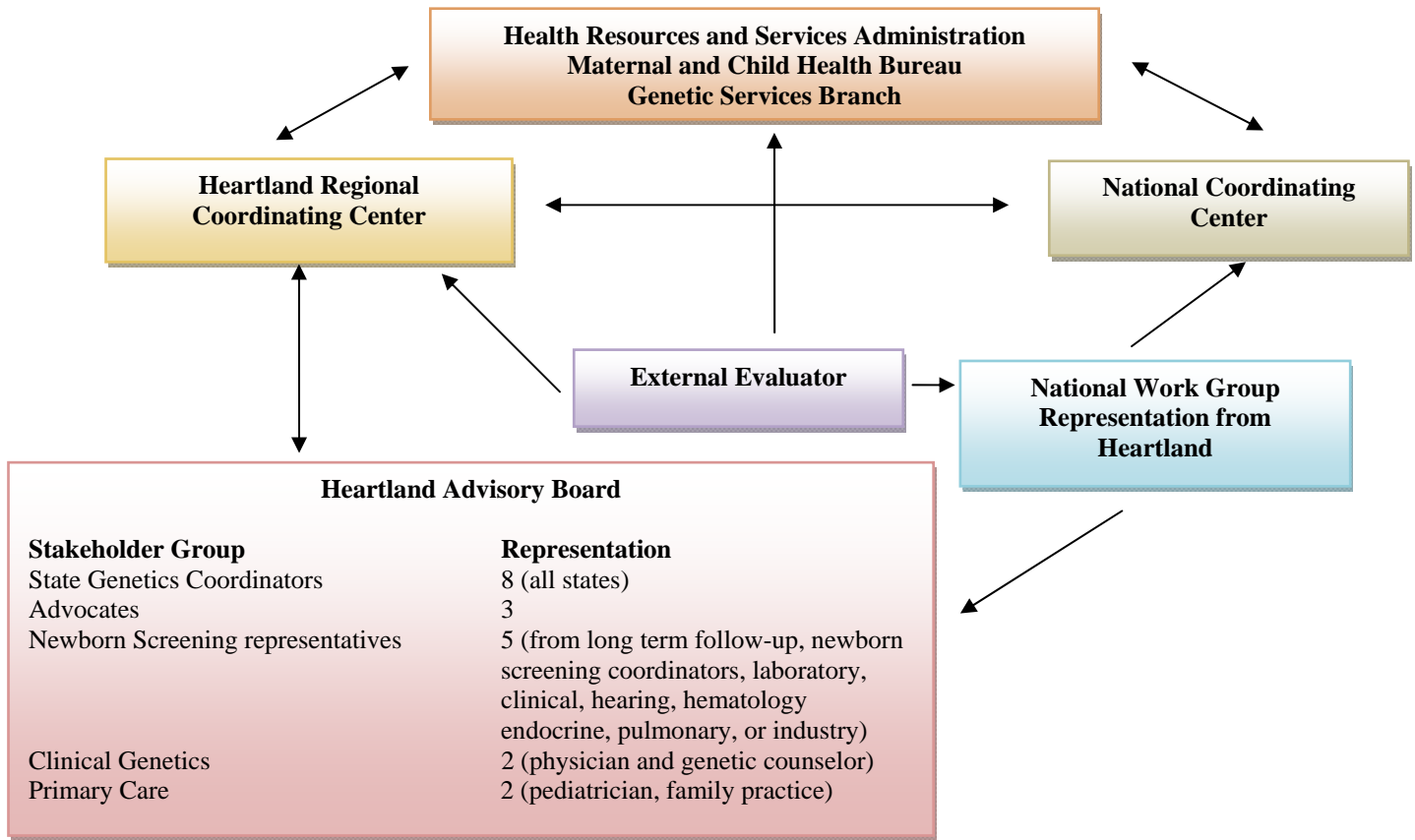
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Heartland Genetics & Newborn Screening Collaborative Needs Assessment Systems Framework



Heartland Genetics & Newborn Screening Collaborative Organizational Chart



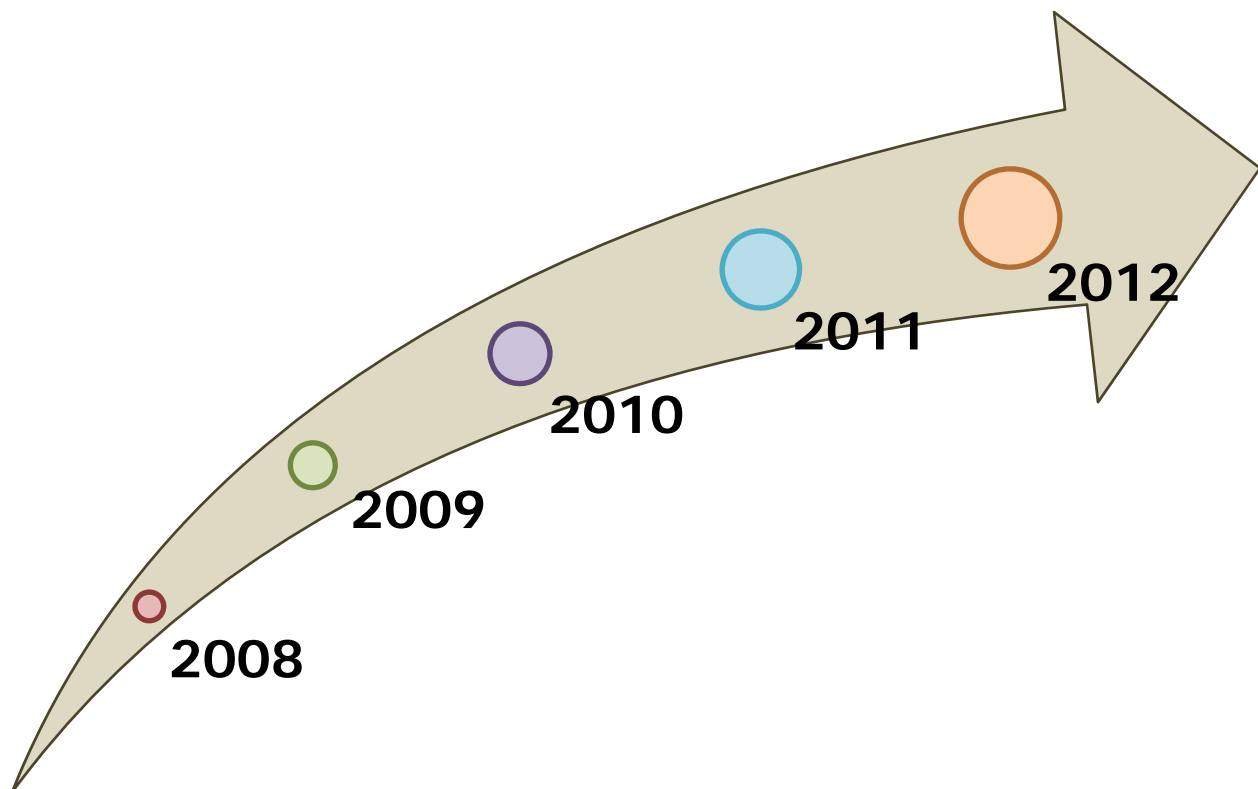
Heartland Genetics & Newborn Screening Collaborative Stakeholder Groups

The Heartland Advisory Board currently has representation from the following stakeholder groups:

- State genetic coordinators
- Medical geneticists
- Newborn screening coordinators
- Newborn screening laboratory
- Primary care providers
- Genetic counselors
- Advocates: consumers, family members and advocacy organizations

As the collaborative continues to grow, representation from these groups will also be added to the Advisory Board:

- Genetic nurses
- Clinical laboratory
- Specialists
- Industry representatives
- Title V: program representatives
- Payer (Insurance) representatives
- Medical Home Leaders
- Other Public Health representatives



Executive Summary

Development of the *Heartland Genetics and Newborn Screening Collaborative Strategic Plan* was a collaborative effort between interested parties from the Heartland Collaborative and Work Group members. The Heartland Genetics and Newborn Screening Collaborative is a network of stakeholders from eight states: Arkansas, Iowa, Kansas, Missouri, Nebraska, North Dakota, Oklahoma, and South Dakota. Funding for development of a regional plan and the ongoing support of the collaborative network is provided by a cooperative agreement from the Genetic Services Branch, Maternal Child Health Bureau, Health Resources and Services Administration (HRSA). This document provides policymakers, genetic stakeholders and others with an overview of the needs of the Heartland region and ongoing action plan with the following mission and goals:

Mission: The Heartland Genetics and Newborn Screening Collaborative includes health professionals and advocates who promote and improve health through quality medical genetics services, clinical laboratory services, professional and public education, genetics research and public policy.

Goal 1: Promote assessment, planning, evaluation, partnering and policy activities to facilitate access to quality clinical genetic services and research for the citizens of the states within the Heartland Collaborative.

Goal 2: Promote genetics education regarding resources, clinical and laboratory services (availability, access, indications, limitations, and benefit), genetic testing, teratogen services, and genomics. Facilitate integration of genetics education into the curriculum of primary & secondary schools, vocational schools, colleges, and schools of health, such as medical schools, residency programs, midwives, nursing schools, allied health, and physician assistants.

Goal 3: Promote quality public health genetics programs in the Heartland by establishing an infrastructure to facilitate networking, education, information sharing, assessment, policy activities, program development and evaluation within the region.

Goal 4: The Heartland Regional Coordinating Center will provide leadership in the region and facilitate activities to promote access to quality clinical genetic services, genetic testing, and public health programs for the citizens of the states in the Heartland Collaborative.

Implementation of the *Heartland Genetics and Newborn Screening Collaborative Strategic Plan* will enhance the capacity of the public health genetics programs within the region to facilitate local access to quality clinical genetic services and to enhance newborn screening and public health programs within each state. Coordination of the regional collaborative is provided by Heartland Regional Coordinating Center headquartered in Oklahoma City, Oklahoma. For more information, please visit the Heartland website www.heartlandcollaborative.org or correspond with the Center, e-mail hrcc@ouhsc.edu or call 405-271-8685.

Heartland Genetics and Newborn Screening Collaborative • Regional Genetics Plan Logic Model • 2006 to 2012

ASSUMPTIONS	PROCESS	OBJECTIVES	GOALS	OVERALL IMPACT
The public and providers will utilize clinical genetic services if they are available, identifiable, accessible, acceptable and useful in meeting health care needs.	Networking; assessment; education; strategic planning; policy activities; directory; best practice model promotion; research & information dissemination .	Clinical genetic services are available, identifiable, accessible, acceptable, useful and of high quality.	Clinical Genetic Services	<p><u>Mission</u> The Heartland Genetics and Newborn Screening Collaborative includes health professionals and advocates who promote and improve health through quality medical genetics services, clinical laboratory services, professional and public education, genetics research and public policy.</p>
A well-informed public and providers will promote genetics as an integral part of the health care delivery system.	Family history campaign; website directory; dissemination of information on reasons for referral to the public health providers & allied health professionals.	Family history, quality genetic testing, & appropriate referrals are fully integrated into the health care delivery system.	Genetics Education	
Genomics education will promote and attract students to pursue genetic careers and improve the public's genetic literacy.	Website & interface with educators.	Attract students to pursue genetic careers and integrate genetics into the curriculum at every level.		
Public health's assessment, assurance, policy, and partnering activities will facilitate integration of quality genetic and population-based services into the healthcare delivery system across the lifecycle.	Networking; promote professional education; technical assistance; policy activities; promote best practice models; assessment & evaluation.	Expert public health workforce; integrate genetics into public health programs; full-time State Genetic Coordinators and active advisory councils each state; quality and equitable public health programs.	Public Health Infrastructure	
An effective Regional Coordinating Center will increase collaboration and facilitate equitable population-based and individual genetic services in the region.	Maintain effective advisory council and committee structure; host website, web-casts and listserve; ensure modes exist to timely share information such as Heartland newsletter; host annual meetings; maintain Heartland directory.	Increase collaboration and assessment in the region; increase awareness and communication; facilitate regional plan implementation and evaluation.	Heartland Regional Coordinating Center Leadership Strategies	
The Regional Coordinating Center will promote research projects that will advance best practices in the region.	Disseminate grant announcements and support innovation at the state levels via funding collaborative regional projects.	Attract funds to the region; promote collaborative, innovative project activities in the region.		

ARKANSAS IOWA KANSAS MISSOURI NEBRASKA NORTH DAKOTA OKLAHOMA SOUTH DAKOTA

Heartland Genetics and Newborn Screening Plan – 2006 to 2012

Mission - The Heartland Genetics and Newborn Screening Collaborative includes health professionals and advocates who promote and improve health through quality medical genetics services, clinical laboratory services, professional and public education, genetics research and public policy.

Clinical Genetic Services – Goal 1

Promote assessment, planning, evaluation, partnering and policy activities to facilitate access to quality clinical genetic services and research for the citizens of the states within the Heartland Collaborative.

Assumption: The public and providers will use clinical genetic services (CGS) if they are available, identifiable, accessible, acceptable and useful in meeting health care needs.

Objective	Process	Expected Change
Available	Networking, strategic planning, policy activities	Each state in the Heartland will have local clinical genetics services.
Identifiable	Web-based	Increase awareness of CGS in the Heartland.
Accessible	Network, assessment and strategic planning (including telemedicine options)	CGS are available in each state and are accessible to all needing services.
Acceptable	Education, assessment	Best practice models are implemented to ensure services are acceptable to families.
Useful	Education	Health care providers and the public will have increased awareness of the benefit of CGS.
Quality	Network, promote best practice models, technical advances (research and information dissemination)	Heartland CGS providers utilize information gained through the collaborative to enhance service delivery.

Genetics Education – Goal 2

Promote genetics education regarding resources, clinical and laboratory services (availability, access, indications, limitations, and benefit), genetic testing, teratogen services, and genomics. Facilitate integration of genetics education into the curriculum of primary & secondary schools, vocational schools, colleges, and schools of health, such as medical schools, residency programs, midwives, nursing schools, allied health, and physician assistants.

Assumption #1: A well-informed public and providers will promote genetics as an integral part of the health care delivery system.

Objective	Process	Expected Change
Family History	Family History Campaign	Family histories will be fully integrated into the health care delivery system.
Genetic Testing	Awareness Campaign	Public and providers will become more familiar with the limitations and benefits of genetic testing.
CGS Referral	Web-based, dissemination of information on reasons for referral to the public and health care providers	Increase knowledge of needs for CGS referral and an increase in referrals to CGS.

Assumption #2: Genomics education will promote and attract students to genetics careers and improve the public's genetic literacy.

Objective	Process	Expected Change
Attract students to careers in genetics	Awareness Campaign	Increase in knowledge of careers in genetics and an increase in applicant pool for Heartland genetics workforce.
Integrate genetics into the curriculum at every level	Interface with educators	An increase in the amount of genetics information taught at every level.

Public Health Infrastructure – Goal 3

Promote quality public health genetics programs in the Heartland by establishing an infrastructure to facilitate networking, education, information sharing, assessment, policy activities, program development and evaluation within the region.

Assumption: Public health’s assessment, assurance, policy, and partnering activities will facilitate integration of quality genetic and population-based services into the healthcare delivery system across the lifecycle.

Objective	Process	Expected Change
Achieve and maintain an expert public health workforce in the Heartland	Network, promote professional education, technical assistance	Improved public health programs in the region.
Integrate genetics into all aspects of state public state public health programs	Educate, technical assistance, networking	Genetics an integral component of all relevant public health programs (such as, CSHCN, MCH, and Chronic Disease).
Achieve dedicated full-time State Genetic Coordinators (SGC) in each state	Policy, activities, technical assistance	Each state will have a dedicated full-time SGC.
Achieve genetics advisory councils in each state	Technical assistance	Each state will have an active genetics advisory council.
Quality & equitable Newborn Screening Programs (short-term and long-term follow-up)	Promote best practice models, assessment and evaluation, technical assistance, networking	Newborn Screening programs are equitable in the Heartland.
Quality & equitable genetics programs in the Heartland	Promote best practice models, assessment and evaluation, technical assistance, networking	Equitable genetics programs in the Heartland.
Disaster plan for Newborn Screening programs in the Heartland	Develop plan	Heartland plan that provides a response capacity to assist Heartland Newborn Screening programs in continuing newborn screening services.

Heartland Regional Coordinating Center – Goal 4

The Heartland Regional Coordinating Center will provide leadership in the region and facilitate activities to promote access to quality clinical genetic services, genetic testing, and public health programs for the citizens of the states in the Heartland Collaborative.

Assumption #1: An effective Regional Coordinating Center will increase collaboration and facilitate equitable population-based and individual genetic services in the region.

Objective	Process	Expected Change
Increase collaboration for assessment and action in the region	Maintain Advisory Board and Work Groups	Increased assessment and action capacity to improve CGS and public health programs in the region.
Increase awareness of regional activities & program successes	Heartland web site, hosting webcast, timely sharing of information; monthly conference calls	Public health, geneticists and other stakeholders will increase activities in the region.
Increase communication between stakeholders in the region	Annual meeting, list serve, maintain updated directory, host interactive web cast, newsletter	Public health, geneticist and stakeholders will communicate on a regular basis with colleagues throughout the region.
Facilitate implementation and evaluation of the regional plan	Report to Heartland RC Staff	Plan is implemented, refined and evaluated.

Assumption #2: The Regional Coordinating Center will promote research projects that will advance best practices in the region.

Objective	Process	Expected Change
Attract funds to the region for research projects	Disseminate grant announcements for projects that meet the goals & objectives of the regional plan	Increase implementation activities of the Regional Plan.
Promote project innovation to facilitate the achievement of the goals & objectives of the regional plan	Annual grant cycle	Increase implementation activities of the Regional Plan.

Acknowledgments

Steering Committee

(June 2004 – February 2005)

Merlin Butler (MO)
Debra Collins (KS)
Lucy Fossen (SD)
John Martsolf (ND)
Julie Miller (NE)
Kim Piper (IA)
Mary Riske (ND)
Sharmini Rogers (MO)
Brad Schaefer (NE)
Jackie Whitfield (AR)

State Genetics Coordinators

Past and Present

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Jamey Kendall (KS)
Pam King (OK)
Julie Miller (NE)
Kim Piper (IA)
Mary Riske (ND)
Sharmini Rogers (MO)
Sharon Vaz (OK)
Jackie Whitfield (AR)

Advisory Board Members

(2008-2009)

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Leslie Himstedt (AR)
Majed Dasouki (KS)
Amy Brower (NE)
Lucy Fossen (SD)
Jamey Kendall (KS)
Jackie Whitfield (AR)
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Support

The Heartland Genetics and Newborn Screening Collaborative thanks the Health Resources and Services Administration (HRSA)- Maternal and Child Health Bureau (MCHB)-Genetic Services Branch for funding the work of this collaborative through the Heritable Disease Program, Grant U22MC03962 with a cooperative agreement with the University of Oklahoma.

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