

# State of the Heartland Region 2014

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# Overview: 2012 - 2017

- Three funding cycles
  - October 2004 – May 2007
  - June 2007 – May 2012
  - June 2012 – May 2017

# Heartland Mission

- The Heartland Genetics and Newborn Screening Collaborative is focused on ensuring the best possible outcome for individuals with heritable disorders and optimizing the health of the population throughout the life cycle by improving understanding and awareness of genetics; expanding access to health care; and translating new findings to improve the quality of care within an eight-state region.

# Heartland's Goals

- 1) Continue to ensure that individuals with genetic disorders and their families have access to quality care and appropriate genetic expertise and other subspecialty expertise;
- 2) apply the translation of genome-based knowledge, genomics best practices, and new technologies to education and training, services and dissemination to improve population health; and
- 3) quantitatively and qualitatively evaluate through program evaluation outcomes of projects undertaken to accomplish the goals.

# 2012 – 2017 characteristics

- HRSA priority areas
- Length of projects
- National evaluation
- ACA
- HRCC changes
  - award recipient
  - staffing

# Planning process

- Began in summer 2011
  - Efforts that had been started and work group interests
  - Survey Monkey™
  - Prioritization exercise at the Bismarck meeting
  - Advisory Board final prioritization
  - Mapping Heartland priorities to the HRSA priority areas

# HRSA priority area 1

- ***Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care.***
  - Objective 1: Increase the number and diversity of the referral indications for telemedicine patient visits in the Heartland.
    - Strategy 1: Prioritize pilot project funding for telemedicine clinic expansion.
    - Strategy 2: Provide technical assistance to new users of telemedicine for the delivery of public health or clinical genetics services.
    - Strategy 3: Educate genetics residents, genetic counseling students, and those in practice less than five years in partnership with Western States RC.

# HRSA priority area 1

- ***Treat in the context of a medical home that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care.***
- Objective 2: Use the Individualized Health Plan (IHP) to enhance coordinated, continuous and family-centered care for children with genetic conditions in the school setting.
  - Strategy 1: Build on the IHP efforts from the Kansas Integrated Community Systems (D-70) grant.



# HRSA priority area 1

- ***Treat in the context of a medical home that provides accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective care.***
- Objective 3: Increase Heartland pediatric genetics providers' knowledge of and practice behaviors in healthcare transition for youth with genetic conditions.

# HRSA priority area 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.***
  - Objective 1: Increase PCPs' access to tools and resources for the initial evaluation, follow-up and monitoring of patients with genetic disorders.
    - Strategy 1: Disseminate results, tools, and resources of the pilot project, *"A novel approach in telegenetic services—pediatrician and genetic counselor team"*
    - Strategy 2: HRCC will update members about national efforts in developing templates for management of patients with genetic conditions.
    - Strategy 3: Complete the "Heartland collaborative partners program" and evaluate outcomes.

# HRSA priority area 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.***
  - Objective 2: Enhance the Heartland's EHDI programs through resource sharing and education.
    - Strategy 1: EHDI exchange program
    - Strategy 2: Support genetics education of EHDI coordinators, audiologists, educators, speech/language pathologists, otolaryngologists, parents, patients, and advocates in the region.

# HRSA priority area 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.***
  - Objective 1: Heartland will initiate an information system to facilitate Heartland states' adoption of DSACHDNC recommendations related to newborn and child screening and genetic follow-up and treatment services.
    - Strategy 1: Develop an implementation toolkit for Heartland states.
    - Strategy 2: Monitor local, regional and national activities related to new conditions and DSACHDNC recommendations to identify opportunities for Heartland states to participate in pilots, clinical practice guidelines, short and long-term follow-up of NBS identified patients...

# HRSA priority area 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.***
  - Objective 1: Improve state systems to reflect best practices in LTFU by increasing the specificity of NBS, establishing an approach to the LTFU of patients, incorporating electronic health information, and expanding the number of conditions for which screening tests are available.
    - Strategy 1: Conduct regional NBS workshop for key stakeholders.
    - Strategy 2: Facilitate states' adoption of case definitions for the recommended uniform screening panel.
    - Strategy 3: Link Heartland clinicians to clinical, LTFU databases, such as IBEM-IS/IBEM-C.

# HRSA priority area 10

- ***Any other program priority that addresses the needs of the region and the program goals.***
  - Objective 1: Expand the implementation of the Genetic Systems Assessment tool.
    - Strategy 1: Revise tool based on Heartland implementation experience.
    - Strategy 2: Sustain GSA in the Heartland.
    - Strategy 3: Plan and execute national rollout of the GSA tool.

# HRSA priority area 10

- ***Any other program priority that addresses the needs of the region and the program goals.***
  - Objective 2: Pilot project program
  - Objective 3: Sustain emergency preparedness in the Heartland region

# HRSA priority area 10

- ***Any other program priority that addresses the needs of the region and the program goals.***
  - Objective 4: Facilitate communication and linkages of Heartland providers through a variety of methods.
    - Strategy 1: HRCC coordinate activities that promote communication and linkages.
    - Strategy 2: Heartland website
    - Strategy 3: National work groups



# HRSA priority area 10

- ***Any other program priority that addresses the needs of the region and the program goals.***
  - Objective 5: Hispanic access project