



**Heartland Genetics and NBS Collaborative:
Annual Evaluation 2011-2012**
What has been accomplished? Where do we go from here?




What were the results of Heartland members' research efforts?

A cartoon illustration of a scientist character with a large nose, wearing a white lab coat and a bow tie. He is holding a flask with a stopper in his right hand. Below the character is a small, empty rectangular box.


Key Finding

- Evidenced based treatment protocols improve health status- IBEM

130 patients

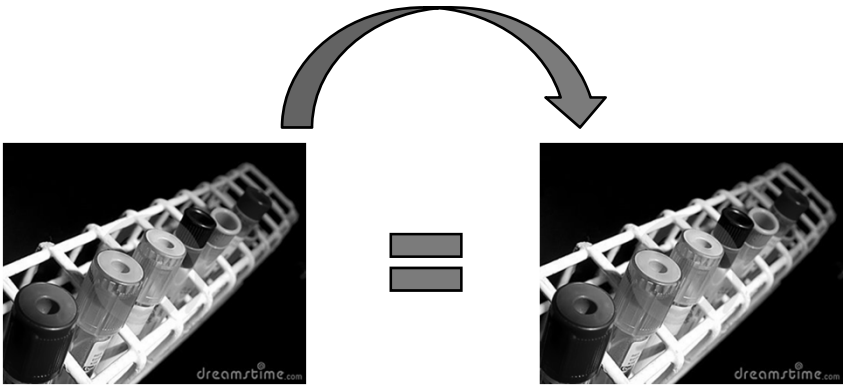


\$25,994



Key Finding

- The capacity for adequate and timely back-up services was demonstrated for emergency backup laboratory services.

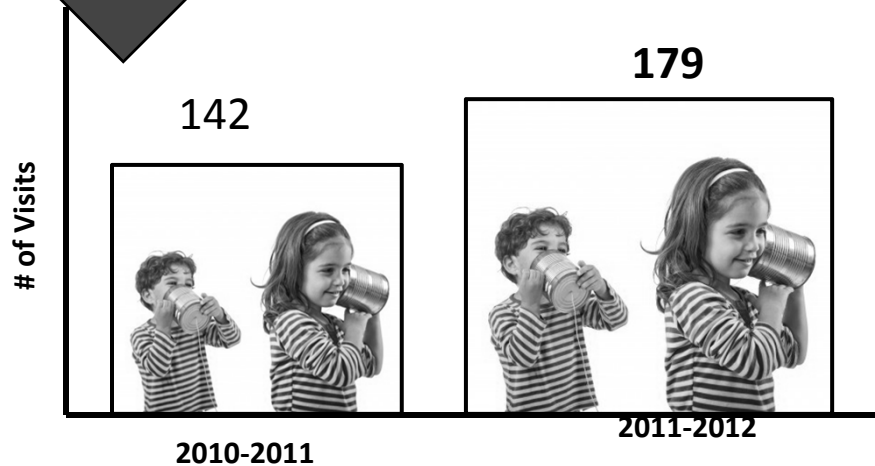


To what extent has Heartland activities improved access to quality genetics services?



Key Finding


- . Telehealth has increased access to genetics services and decreased wait time.



Key Finding

- Learning collaborative provided guidance to genetic practitioners to introduce transition tools to a patient group highly in need of transition guidance .


- Genetics providers lack resources to aid patients in transition process



A 3D illustration of a dark grey toolbox with the words "Tool Kit" printed on the front. The toolbox is open, and several tools are visible inside, including a wrench, a screwdriver, a pair of pliers, and a pencil.

Key Finding

- Heartland has established a validated Genetics Systems Assessment



A map of the Heartland region, which includes parts of Missouri, Illinois, and Arkansas. The map is divided into four horizontal sections with the following text: "Heartland", "Genetics", "and Newborn", "Screening", and "Collaborative". A DNA double helix is overlaid on the map.

8 Heartland states completed assessment process

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Continuous Improvement Process

Key Finding

- Early Hearing Detection Intervention (EHDI) programs prioritize networking to improve their practices

- Exchange visits initiated to:
 - Increasing consistency in hospital reporting
 - Improving data systems
 - Exploring web-based systems,
 - Improve long-term follow-up rates

How did Heartland RC support education?



- College of Nursing Education Programs successfully integration of genomics into their curriculum.

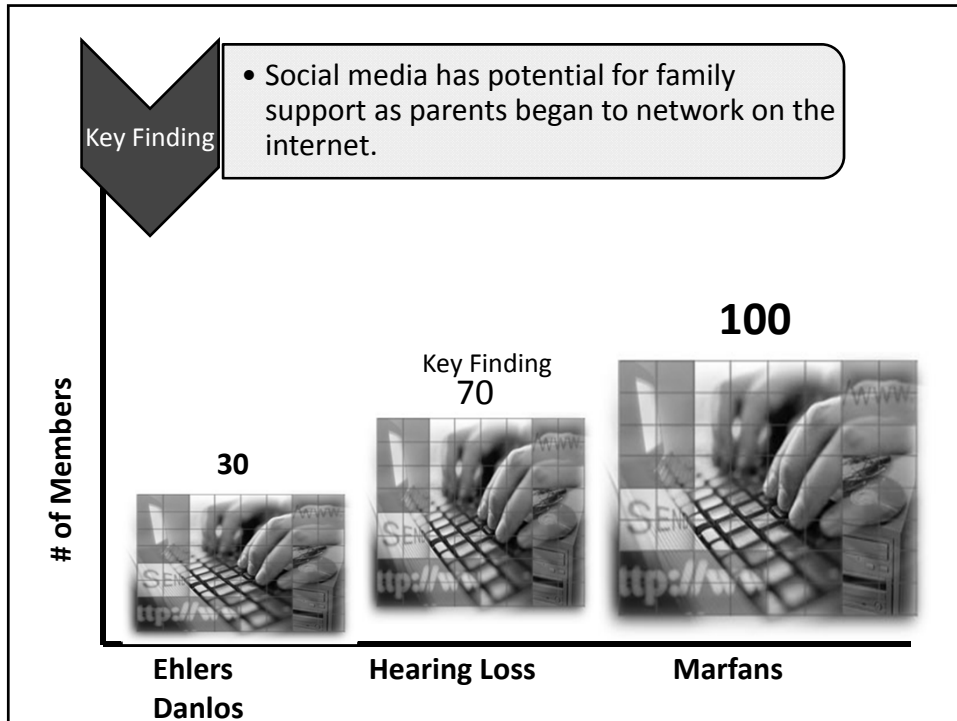
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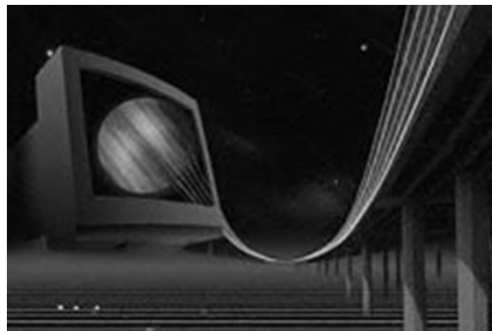
**Achieved
Accreditation**

What were the outcomes of family support activities?






To what extent did Heartland infrastructure facilitate networking and information sharing?

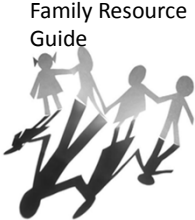


Key Finding


- Heartland Collaborative disseminates findings of their work using multiple modalities.



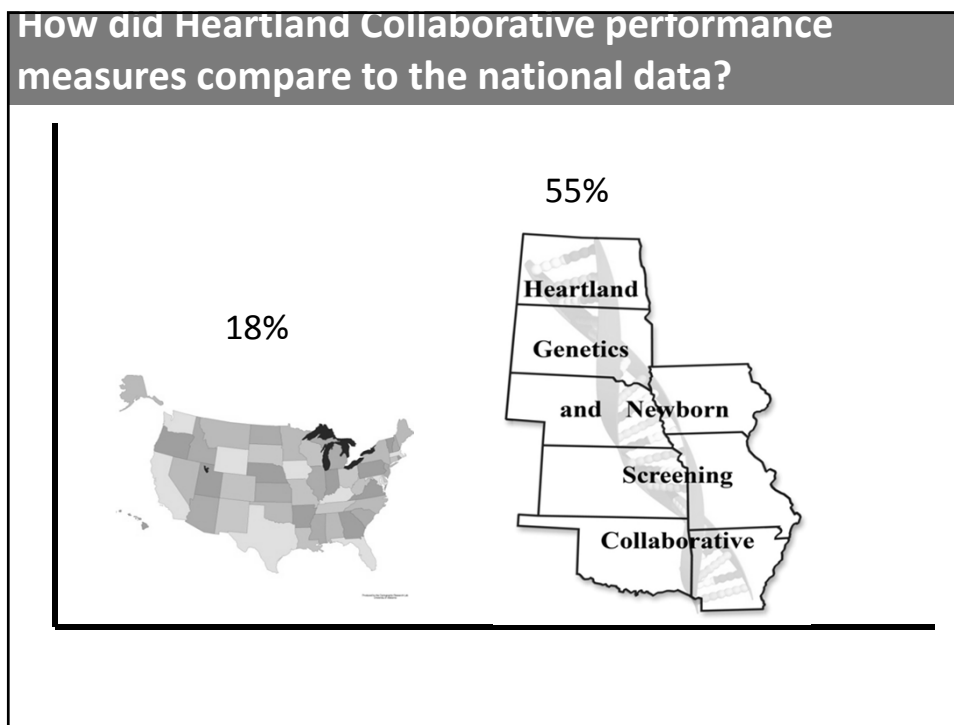
Website



Family Resource Guide



conferences
& meetings





Evaluation Objective



Healthy People 2020:

Increase the proportion of patients whose doctor recommends personalized health information resources to help them manage their health.





Measuring the impact!



- How much did you do?
 - PCP participation in meeting
 - Other activities
- How well did you do it?
 - Immediate feedback from PCPs
- Is anyone better off?
 - Baseline and follow-up survey to determine change in practice



Reflections and Questions

