


Annual Evaluation 2009-2010



Heartland
Genetics
and Newborn
Screening
Collaborative

Heartland Genetics and Newborn Screening Collaborative

Goal 1: Facilitate access to quality clinical genetic services for the citizens of the states with the Heartland Collaborative

- 100% of the states contributed to the Region 4 Laboratory Performance Priority project.
- 3 states genetics' centers submitted data to Region 4's Inborn Errors of Metabolism Information System (IBEM-IS).
- Families access to genetic services increased due to the new collaboration between University of Arkansas and Wesley Medical Center Telehealth Project.

Goal 2: Promote genetics education and facilitate integration of genetics education into curriculum of schools.

- Faculty and partner affiliates supported LEND programs through guest lectures.
- Data from all of the Heartland states was collected and contracted staff will be finalizing the Resource Guide in 2010-2011.

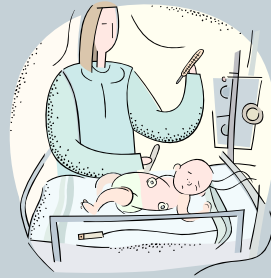
Consultation to nursing education programs to support their integration of genomics into the nursing curriculum.

- **Findings based on Change Agent:**
 - Timing of the consultation was excellent as they are working towards accreditation.
 - Faculty resources were viewed as valuable and faculty had already accessed several.
 - The consultation process /self-assessment was viewed positively
 - Faculty felt that the task was FEASIBLE and not OVERWHELMING.

Goal 3: Promote quality public health services through infrastructure support.

• **Newborn Screening Exchange**

- 5 States participated
- Purpose: to improve their short-term follow-up (STFU) and/or long-term follow-up (LTFU) programs
- Evaluation was completed using the Program Evaluation and Assessment Scheme (PEAS)



Findings:

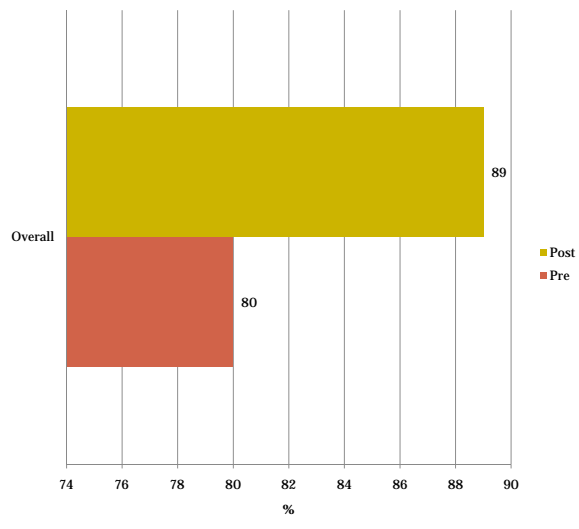
Increase in STFU procedural steps.

States made modifications to their processes (developed web-site with resources for providers and their families).

Opportunities to network were viewed as valuable.

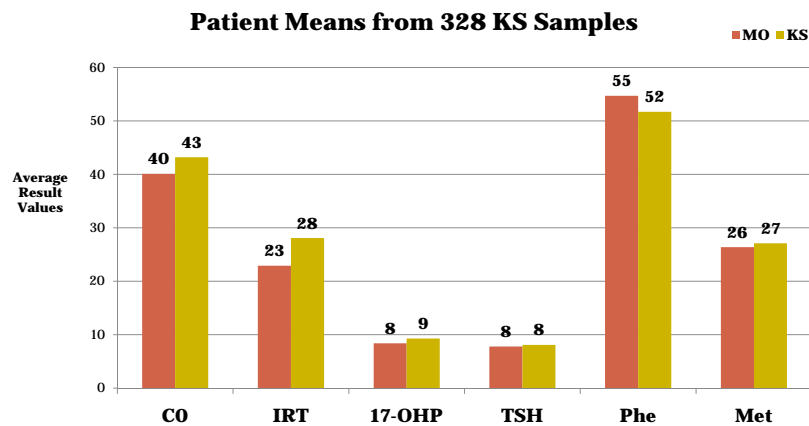
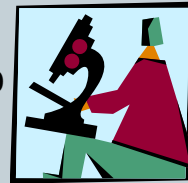
Both sending and receiving programs benefited.

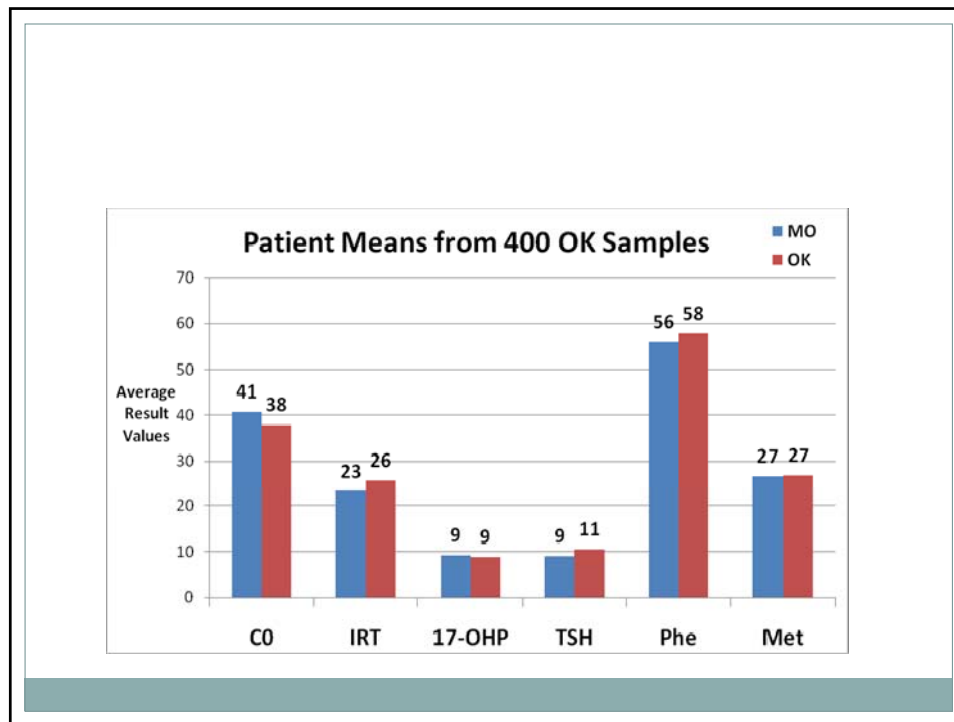
% of PEAS Items Completed: STFU



NBS Back-Up Testing and Quality Assurance Project

- Collaborative project with The University of Iowa and Missouri Public Health Laboratory to improve emergency preparedness
- Completed fully functional drills in Nebraska, Arkansas, Oklahoma, Minnesota, and Kansas.
- Planned with their partner states through onsite visits and conference calls
- Drills took place in April and May with 300-400 specimens per site being re-analyzed.





Findings:

- EMAC process was successful in providing a structure under which to conduct the drills
- The Heartland Collaborative is the first region to have established, validated NBS laboratory back-up procedures in place for all states within the region.
- The drills demonstrated that screening results were very similar to the home state's laboratory findings.
- Work with Minnesota demonstrated that their lab could serve as a back-up to Iowa and Missouri, as well as receive back-up services from Iowa and Missouri.

Lessons Learned

- The Project needs to find resources to complete backup drills (in alternating years) to assure continued preparedness for states in the Heartland Collaborative.
- The Heartland NBS Back-up Project procedures have been refined and validated and could be disseminated to other regions for replication.

Sarah Lawrence Scholarship

- Content of the program was valuable/comprehensive /affordable.
- Opportunity to integrate their knowledge both in genetics and public health.
- Increased professional credibility.
- The Capstone Project provided them an opportunity to implement a project that was applicable to their work.
- Invaluable networking .
- Program could be strengthened :
 - integrating the content of genetics and public health
 - provide more information on public health.

Dissemination of Information and Resources

Web Traffic	Results base on 3 months Data
Total Visits	3,660
One-time Visitors	1,996
Repeat Visitors:	1,664
Total Page Views	11,376
Average Page Views Per Visit	3.11

Goal: Provide leadership in the region to promote access to services, collaborative research and public health programs.

- Action steps for 2010-2011
 - Convene a work group from the Advisory Board that will develop recommended bylaws to include:
 - ✦ Structure
 - ✦ Governance
 - ✦ Decision-making processes

Summary of National Performance Measures: Comparison with National Data



Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED CARE COORDINATION		
Measure A1: Increase % of states with collaborations and facilitated by Regional Collaborative (RC) between PCPs and specialty providers to improve care coordination.	87.5 % of states	66.7% of states and territories

Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED ACCESS		
Measure B1: Increase # of genetic services visits and NBS follow-up specialty visits through distance strategies.	292 visits	517 visits

Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED EMERGENCY PREPAREDNESS/CONTINGENCY PLANNING		
Measure C1: Increase % that have received current materials or assistance from the RC on emergency preparedness/contingency planning for NBS and genetic services.	75% of states	83% of states and territories

Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED FOLLOW-UP OF CHILDREN IDENTIFIED WITH HERITABLE DISORDERS THROUGH NBS		
Measure D1: Increase % of states that made recommendations on implementing the ACHGDNC recommended NBS panel.	100%	98% of states and territories
Measure E1*: Increase % of states with systems in place to track entry into clinical management for newborns who are diagnosed with conditions mandated by their State-sponsored newborn blood spot screening programs.	100%	98% of state and territories
Measure E2: Increase % of states with systems in place to track entry into clinical management for newborns who are diagnosed with hearing loss.	100%	65% of state and territories
Measure E3*: Increase of system to track receipt of clinical services and/or health outcomes for children who are diagnosed with condition(s) by State-sponsored newborn blood spot screening program.	50%	13% of state and territories

*Performance Measures Reported Nationally by State


Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED EDUCATION OF PCPS ABOUT TREATMENT OF PEOPLE WITH HERITABLE DISORDERS		
Measure F1*: Increase the NBS programs that disseminate "just-in-time/point-of care" information on specific heritable disorders to primary care providers.	100%	96% of the states and territories

Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED REGIONAL PLANNING AROUND DELIVERY OF GENETIC SERVICES WITH HERITABLE DISORDERS		
Measure G1: Increase the % of Regional Collaborative (RCs) that have completed a regional genetic services plan.	100%	86% of RCs
Measure G2: Increase in the % of RCs that have reviewed and/or updated their regional genetics services plan at least every two years.	Not updated in 2009-2010	71% of RCs

Evaluation- How Can It Support Your Projects

- Are there questions you would like to have answered?
- Do you want support reflecting on data that you've collected?





Celebrate!!

Improved processes

Improved access to services

Improved skills and knowledge

