Heartland Genetics and NBS Collaborative

Annual Evaluation Results

September 2011

Goal

- Facilitate access to quality clinical genetic services

Strategy

- Lab Performance Project (Region 4)
- IBEM-IS Project (Region 4)
- Youth Transition Project
- Clinical genetics survey

Research Opportunities

100% of the states contributed to the Region 4 Laboratory Performance Priority project.

Three states genetics' centers (OK, SD, MO) participated in Region 4's Inborn Errors of Metabolism Information System (IBEM-IS). One (NE) has just completed the IRB process.

Telehealth

Kansas (Wesley Medical Center) in partnership with the University of Arkansas Medical Center used telehealth strategies to increase access to genetic services. 2009-2010. 142 visits completed with an average of 8 per month.

Telemedicine Manual for Clinical Genetics Services was completed.

University of Nebraska Medical Center

Transition Project

Two Heartland genetics clinics (Wesley Medical Center and Oklahoma Health Sciences) are partnering with a national NHCTC Transition Pilot study (PI-Dr. Laura Pickler) to develop procedures to support youth transition to adult health care services.

Partners in a national Learning Community.

Goal

- Promote genetics education

Strategy

- Utah MedHome Portal
- LEND
- Family Resource Guide
- Nursing Consultation Project

Education Activities

Prader-Willi syndrome and Medium Chain Acyl-CoA Dehydrogernase Deficiency (MCADD) modules are posted on Utah MedHome Portal.

Partnerships with LEND:

- LEND parent representatives
- LEND students partner in Transition Project

The Family Financial Guide was completed

Nurse Consultation project

Purpose:

- To provide consultation to nursing education programs to support their integration of genomics into the nursing curriculum.

Targeted Universities/Colleges:

- Univ of Dubuque, Briar Cliff College, Univ of North Dakota

Quality of the Consultation

The timing and the content of this consultation was excellent

The self-assessment process was very helpful as it assisted faculty in identifying their own skills and knowledge

A knowledgeable consultant who was excellent in facilitating the review

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“The consultation helped to de-mystify “genomics” and helped us to see how we could infuse this content into our courses.”

Outcomes

One University received their accreditation

The remaining University is preparing for the accreditation that is scheduled in 2012.

Goal

- Promote quality public health programs establishing supportive infrastructure

Strategy

- Genetics System Assessment
- PKU Camp
- NBS Back-Up Project
- Disseminate Information
- iLibrary

Genetics System Assessment (GSA)

The GSA includes: indicators of quality genetics services/corresponding measures.

A pilot completed in Hawaii and Washington.

A poster presented at the Academy of Health National Public Health meeting.

NBS Back-Up Testing Project (Iowa/MO): Dissemination Activities

Project directors disseminated model through the Association of Public Health laboratories and the National Coordinating Center.

Currently they are also working to complete an article that will further disseminate their work.

University of Nebraska Medical Center

Heartland Dissemination Activities

Primary Activities: E-newsletter, list serve (107 topics) and web-site

Web Traffic from June 1, 2010 through May 31, 2011	
Total Visits:	3,681
One-time Visitors:	2,468
Repeat Visitors:	1,213
Total Page Views:	10,092
Avg Page Views Per Visit:	2.75

Goal

- Provide leadership to promote access to quality clinical genetic programs

Strategy

- Leadership activities

Leadership Activities

Established and adopted Heartland Collaborative Bylaws

Initiated Strategic Planning for new 5 year grant application

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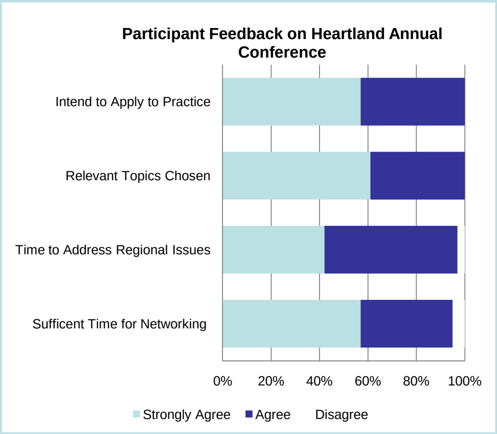
Participant Feedback of Conference



Ratings

Comments

University of Nebraska Medical Center

Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED CARE COORDINATION		
Measure A1: Increase % of states with collaborations facilitated by Regional Collaborative (RC) between PCPs and specialty providers to improve care coordination.	50 % of states	70%. 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.	613 visits	1094 visits

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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	94% of states and territories

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 FOLLOW-UP OF CHILDREN IDENTIFIED WITH HERITABLE DISORDERS THROUGH NBS		
Measure D1: Increase % of states that made recommendations on implementing the SACHDNC recommended NBS panel.	87.5%	98% of states and territories
Measure D1: : Increase % of states that made recommendations on implementing the SACHDNC recommended NBS panel including SCID.	37.5%	35% 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%	100% 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.	87.5%	83% of state and territories
Measure E3*: Increase % of states with a 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%	17% of state and territories

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Outcome Measure	Region 5 Results	National Results
DOMAIN: IMPROVED REGIONAL PLANNING AROUND DELIVERY OF GENETIC SERVICES WITH HERITABLE DISORDERS100		
Measure G1: Increase the % of Regional Collaboratives (RCs) that have completed a regional genetic services plan.	100%	100% 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.	Updated in 2009-2010	100% of RCs

Heartland Collaborative

STRATEGIC PLANNING PROCESS

Steps Taken in the Planning Process

Step 1: Advisory Board drafted a vision, mission, and identified strengths, challenges, opportunities, &

Step 2: Collaborative members provided feedback and identified strategic areas

Step 3: Collaborative members prioritized strategic areas

Vision

All individuals with genetic conditions within the Heartland Region achieve optimal health across the life course.

Mission

The mission of the Heartland Genetics and Newborn Screening Collaborative is to improve health of individuals with genetic conditions by: increasing understanding of genetics; expanding access to patient-centered healthcare systems; advancing translational research and quality improvement.

Values

1) Addressing patients' health care needs across the life course;
2) Empowering patients and their families, health care providers, and policy makers through the exposure to accurate genomics information;
3) Facilitating linkages and partnerships between state programs, clinical providers, families, and patients that enhance quality services and resources, improve systems and drive best practices;
4) Fostering new knowledge discovery in genomics and public health through new initiatives and partnerships;
5) Adhering to ethical principles of nonmaleficence, beneficence, respect for autonomy, justice, and fairness for the states and persons in our region.

Next Steps: *Planning Activities for Strategic Areas*

1. Enhance newborn screening programs
2. Promote high impact initiatives & new knowledge discovery
3. Support capacity for long term follow-up care
4. Strengthen relationships with related partners (EHDI, Hematology)
5. Support providers on dramatic changes due to rapidly changing technology that impacts field.

Directions

Each group will be assigned a strategic area.

As a group brainstorm activities for that area. (15 minutes)

Round robin activity – add to each strategic area your groups activities. (10 minutes for each area)

At your last area – each group will prioritize the top 4 activities. (Dot exercise and consensus) and report out (30 minutes)

Questions??