



The Regional Genetics Collaboratives: Looking Back Over Last Year's Outcomes and Activities

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The National Evaluation of the Regional Genetics Collaboratives (RCs)

- **Evaluation Workgroup was convened in 2007 to develop a national evaluation for the RCs.**
- **Workgroup consists of 1 representative from each of the RCs and from HRSA.**
 - Chair is Gloria Weissman (consultant to the NCC).
 - Heartland is represented by Barbara Jackson (Lori Williamson is Alternate).
- **Workgroup continues to meet to:**
 - Review data submitted annually by RCs;
 - Based on data, make minor changes to some of the outcome measures; and
 - Review draft of annual report on data before its official submission to HRSA.



The National Evaluation of the RCs

- ◆ **The workgroup developed outcome measures to:**
 - (1) measure the progress being made by the RCs toward the major goals of this initiative; and
 - (2) identify areas in which collaboration among and technical assistance from the RCs, the NCC, and HRSA could help moving these goals forward.
- ◆ **Emphasis on finding common outcome measures for all of the RCs to track and report on annually.**
- ◆ **National evaluation always intended to be complemented by the individual evaluations undertaken by each of the RCs.**



Outcome Measures for the National Evaluation

- ◆ **7 evaluation domains and 10 common outcome measures selected.**
 - **4 outcome measures proposed for consideration as official Maternal and Child Health Bureau (MCHB) performance measures:**
 - improved collaboration between primary and specialty (including genetic) providers;
 - short-term follow-up;
 - long-term follow-up; and
 - distribution of information on genetic conditions to primary care providers.
- ◆ **Of the 10 outcome measures reported to HRSA:**
 - data on the 4 proposed MCHB performance measures reported both by each individual RC and as a total;
 - for the other 6 measures, only a total is are reported.



Linking Outcomes and Activities

- ◆ In looking at the evaluation data, it is important to remember that the activities, emphases, and structures of the RCs vary considerably.
- ◆ In addition, several of the RCs have received additional funding for certain activities, i.e., follow-up activities and lab quality assurance.



The Activity Matrices

- ◆ To help identify activities and strategies helpful in achieving progress toward these goals, beginning in 2005, the NCC also developed a matrix of RC activities.
- ◆ Now there are 2 matrices:
 - Completed activities; and
 - Current and planned activities.
- ◆ Matrix updates:
 - Regularly by the RCs; and
 - On conference calls that take place at least 3 times a year between the staff of each RC, the NCC, and HRSA.



First Year Data from the National Evaluation

- ◆ Data presented today (“First Year Data”) cover the period December 1, 2007 to November 30, 2008.
 - In addition, December 1, 2007 baseline data were collected on measures D1, E1, and G1.
- ◆ Reporting schedule designed to allow the RCs to have full year of data on these outcomes available for their annual progress reports to HRSA.
- ◆ This presentation will discuss some of the first year data and highlight activities related to these outcomes.

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Outcome Measure A1

- ◆ **Outcome Measure A1**: Increase in the percentage of states/territories in the region with collaborations facilitated by the RC between primary care providers (PCPs) and specialty (including genetic) providers to improve care coordination for people with heritable disorders.
 - Evaluation Domain: Improved care coordination for people with heritable disorders.
 - Definition: “Collaborations” may include, but are not limited to: learning collaboratives, work groups, practice models, and consortia.
 - One of the proposed MCHB Performance Measures.



Outcome Measure A1 First Year Data

- ◆ **First Year Data: Percentage of states/territories with collaborations facilitated by the Regional Collaborative between primary care providers (PCPs) and specialty (including genetic) providers to improve care coordination for people with heritable disorders:**
 - **TOTAL: 48% (26/54) of the states and territories**
 - **Region 5: 100% (8/8)**
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Some RC Activities: Collaborations between PCPs and Specialty Providers

- ◆ **Region 2 (NYMAC):**
 - PA and DE projects to initiate MH upon NBS diagnosis; to include delineation of responsibilities, care coordination and communication.
 - Medical Home Work Group distributed an RFA for specialty care/primary care partnership pilot programs. 3 being funded.
 - Evaluation of electronic personal health record system at 3 sites will address communication issues between providers of care for people with special health needs.
 - ◆ **Region 4:**
 - PCPs and specialists participated in session on communication at 2008 Regional Meeting; session had didactic and problem solving components.
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Outcome Measure B1

- ◆ **Outcome Measure B1: Increase in the number of genetic services visits and NBS follow-up specialty visits provided to individuals/families through distance strategies implemented by the regional collaborative.**
 - **Evaluation Domain: Improved access to genetic services for people with heritable disorders.**
 - **Definitions:**
 - “Genetic services visit” is defined as “an encounter between a proband/consultand and a genetics provider.”
 - “NBS follow-up specialty visit” is defined broadly. These visits can include short-term and/or long-term follow-up.
 - “Distance strategies” are defined broadly and may include, but are not limited to: outreach/satellite clinics, formalized long-distance consultation arrangements, and telemedicine approaches.
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Outcome Measure B1 First Year Data

- ◆ **First Year Data: Total number of genetic service visits provided to people with or at risk for heritable disorders through distance strategies implemented by the Regional Collaboratives during the reporting period.**
 - **TOTAL: 502 visits**
 - **Region 5 (Heartland): 238 visits**
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Some RC Activities: Use of Distance Technologies

- ◆ **Region 7 (Western States):**
 - In RC's practice model, specialists from 2 genetics centers provide genetics and metabolic services through telemedicine & outreach clinic visits to AK, Guam, HI, and ID families who live more than 2 hour drive from services or require air travel.
 - Practice model also includes care coordination by community PH nurses and social workers.
 - Have addressed cross-border licensing issues for practice model by having MDs licensed in multiple states.
 - Practice Model being evaluated in terms of satisfaction by families, PCPs, & genetics specialists; collected time & cost data.
 - Seminal results of first evaluation reported at Summit; summary being prepared.
 - Second practice model evaluation planned for 12/09.
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Outcome Measure C1 and First Year Data

- ◆ **Outcome Measure C1:** Increase in the percentage of states/territories in the region that have received current materials or other assistance from the RC on emergency preparedness/contingency planning for newborn screening (NBS) and genetic services.
 - Evaluation Domain: Improved emergency preparedness/contingency planning for NBS and genetic services
 - ◆ **First Year Data:** Percentage of states/territories that have received current materials or other assistance from the RC on emergency preparedness/contingency planning for NBS and genetic services.
 - **TOTAL: 48% (26/54) of the states and territories**
 - **Region 5 (Heartland): 100% (8 of 8 states)**
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Some RC Activities: Emergency Preparedness & Contingency Planning

- ◆ **Region 2 (NYMAC):**
 - Produced wallet-sized emergency cards that reference ACT sheet.
 - Kathy Harris is here and has brought samples.
 - On website as a fill-in, print, and laminate product.
 - ◆ **Region 3 (SERC):**
 - Developed regional Emergency Management Strategic Plan
 - Has done grand rounds and workshops; also exercises for consumers and providers
 - Publications on EP in *NCC Collaborator* and *ACMG Geneticist*
 - Bill Perry assisting other RCs to develop continuity of operations plans (COOPs); presented at Region 2 and Region 6 meetings.
 - ◆ **Region 4:**
 - Working on expansion of MN Emergency Medical Services for Children Information System (MEMSCIS) to include metabolic, endocrine, and sickle cell providers.
 - ◆ **Region 6 (Mountain States):**
 - Pilot project focusing on clinical preparedness in Colorado, Wyoming, and Montana., especially in metabolic centers serving large geographic areas, where emergencies can arise frequently.
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Outcome Measure E1

- ◆ **Outcome Measure E1:** Increase in the percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening programs.
 - **Evaluation Domain:** Improved follow-up of children identified with heritable disorders through NBS.
 - **Definitions:** “Entry into clinical management” means that “a healthcare provider has accepted responsibility for treatment and/or monitoring of the child.”
 - One of the proposed MCHB Performance Measures.
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Outcome Measure E1 First Year Data

- ◆ **First Year Data: Percentage of states/territories with systems in place to track entry into clinical management for newborns who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening programs.**
 - **TOTAL: 93% (50/54) of the states and territories**
 - **Region 5: 100% (8/8)**
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Outcome Measure E2

- ◆ **Outcome Measure E2: Increase in the percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with hearing loss through their State-sponsored newborn hearing screening programs.**
 - **Evaluation Domain: Improved follow-up of children identified with heritable disorders through NBS.**
 - **Definitions: “Entry into clinical management” means that “a healthcare provider has accepted responsibility for treatment and/or monitoring of the child.”**
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Outcome Measure E2 First Year Data

- ◆ **First Year Data: Percentage of states/territories in the region with systems in place to track entry into clinical management for newborns who are diagnosed with hearing loss through their State-sponsored newborn hearing screening programs.**
 - **TOTAL: 65% (35/54) of the states and territories**
 - **Region 5 (Heartland): 100% (8 of 8 states)**
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Some RC Activities: Short Term Follow Up

- ◆ **Region 4:**
 - **Have established group to develop best practices for short-term follow-up of children found positive for hearing disorders.**
 - ◆ **Region 7 (Western States):**
 - **Providing assistance to Guam to develop territory-wide short term follow up for NBS.**
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Outcome Measure E3

- ◆ **Outcome Measure E3:** Increase in the percentage (number) of states/territories in the region with systems in place to track receipt of clinical services and/or health outcomes for children who are diagnosed with condition(s) mandated by their State-sponsored newborn blood spot screening program and/or with hearing loss through their State-sponsored newborn hearing screening programs.
 - Evaluation Domain: Improved follow-up of children identified with heritable disorders through NBS.
 - One of the proposed MCHB Performance Measures.
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Outcome Measure E3 First Year Data (1)

- ◆ In reporting on this measure, the RCs presented data on systems in the states in their region to track receipt of clinical services and/or health outcomes for children diagnosed with 5 groups of conditions:
 - metabolic disorders;
 - endocrine disorders;
 - hemoglobinopathies;
 - cystic fibrosis; and
 - hearing.
 - ◆ In the report to HRSA, data on this measure is reported by condition groups and as a total.
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Outcome Measure E3 First Year Data (2)

- ◆ The percentage (number) of states in each region that have services in place to track receipt of clinical services and/or health outcomes for all children diagnosed with any of these conditions:
 - TOTAL: 15% (8/54) of the states and territories
 - Region 5: 25% (2/8)
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Some RC Activities: Long Term Follow Up

- ◆ 3 RCs received additional priority funding for LTFU activities:
 - Region 1 (NEGC):
 - LTFU Workgroup plans to create data sharing charter for states in region.
 - Workgroup to test feasibility of data collection approaches using the New England Newborn Screening Program LTFU variables.
 - Region 3 (SERC):
 - Conducted focus groups and medical foods survey (with other RCs partnering)
 - Developing evidence- and consensus-based guidelines for LTFU
 - Developing LTFU system requirements
 - Region 4:
 - Inborn Errors of Metabolism Information System (IBEM-IS)
 - Intake and interval surveys for 12 disorders (3 more to be added) and 3 neuropsychiatric surveys are in IBEM-IS;
 - 7 metabolic centers in region already entering data into system
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Some RC Activities: Long Term Follow Up (2)

- ◆ **Other RCs also doing activities related to LTFU.**
 - **Region 6 (Mountain States):**
 - 8-state care plan project (Metabolic Consortium) implementing disease-specific care plans and shared data throughout region.
 - Exploring using CHIRP (Colorado data sharing system) to collect LTFU data.
 - **Region 7 (Western States):**
 - Received supplemental funds for project to compile and publish what is being done on LTFU for VLCADD
 - ◆ **RCs involved in NCC Long Term Follow Up Workgroup activities (Amy Brower's presentation)**
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Outcome Measure G1 and First Year Data

- ◆ **Outcome Measure G1: Increase in the percentage of RCs that have completed a regional genetic services plan.**
 - **Evaluation Domain:** Improved regional planning around delivery of genetic services to people with heritable disorders.
 - **Definitions:** Plan should, at a minimum, include support for optimal diagnosis, genetic counseling, follow-up, and management of people with heritable disorders.
 - ◆ **First Year Data: Percentage of RCs that have completed a regional genetic services plan.**
 - **TOTAL: 86% (6/7) of the RCs**
 - **Region 5 (Heartland): Completed plan in 2006. Available at: <http://www.heartlandcollaborative.org/resources/regional.htm>**
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Outcome Measure G2 and First Year Data

- ◆ **Outcome Measure G2:** Increase in the percentage of RCs that have reviewed and/or updated their regional genetic services plan at least every 2 years.
 - Evaluation Domain: Improved regional planning around delivery of genetic services to people with heritable disorders.
 - ◆ **First Year Data: Percentage of Regional Collaboratives** that have reviewed and/or updated their regional genetics plan during the 2 years prior to the end of the reporting period.
 - TOTAL: 57% (4/7) of the RCs
 - Region 5 (Heartland): Yes. 09/08.
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Some RC Activities: Regional Genetics Plans

- ◆ **Region 4:**
 - Surveyed directors of state agencies, genetics providers, and major medical institutions on needs in:
 - NBS and STFU;
 - LTFU and evaluation of outcomes;
 - community collaboration and family support;
 - public and professional education;
 - implementation of medical homes;
 - access to services for underserved pops; and
 - data systems integration.
 - ◆ **Region 6 (Mountain States):**
 - Conducting surveys in all 8 states on assets and needs related to priority areas.
 - ◆ **Region 7 (Western States):**
 - Ongoing data collection from families, PCPs, genetics specialists through practice model.
 - Annual key informant interviews of state genetics and NBS programs representatives in progress.
 - Collaborators' survey planned for fall 09.
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Next Steps

- ◆ **Year 1 final report:**
 - Submitted to HRSA September 14, 2009.
 - To be disseminated to RCs.
 - Presentation to MCHB staff planned for Fall 2009.
 - ◆ **Working with HRSA to develop official performance measures.**
 - ◆ **Year 2 data to be submitted by December 31, 2009.**
 - Covers period December 1, 2008 to November 30, 2009.
 - ◆ **Data to be compiled by Gloria Weissman:**
 - January to February 2010.
 - ◆ **Workgroup call(s) to review second year data:**
 - March 2010.
 - ◆ **Report on Year 2 data to be drafted:**
 - April to May 2010.
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