

**Data Submission Sheet**  
**Outcome Measure E2**  
**Regional Genetics and Newborn Screening Service Collaboratives (RCs)**

Evaluation Domain:

Improved follow-up of children identified with heritable disorders through NBS.

Outcome Measure:

**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 screening programs.**

Definitions:

“Entry into clinical management” means that “a healthcare provider has accepted responsibility for treatment and/or monitoring of the child.”

Reporting Period:

December 1, 2007 to November 30, 2008; **however, baseline data are to be reported for December 1, 2007**

Data Due:

**Baseline data: December 31, 2007**

December 31, 2008

Date of Data Submission:       **1-11-08**

Region:                   **Heartland (Region 5)**

Name, Title, and Contact Information for Individual Submitting Data:

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Total Number of States/Territories in the Region:       **8 (AR, IA, KS, MO, NE, ND, OK, SD)**

Number 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 screening programs.

**8/8 or 100%**

Data Source:

**Heartland NBS Coordinators**

Comments:

**Please provide, as an attachment, specific information about the state systems that are in place in your region. If possible, include information about: whether the systems include all conditions mandated by the state's NBS program, including hearing screening; and which program(s) is responsible for tracking.**

**Also briefly provide, as an attachment, information about any efforts that are underway to create and improve these systems in the states in your region:**

**Please submit this form and attachments, by mail, email, or fax to:**

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