

**Data Submission Sheet**  
**Outcome Measure E3**  
**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 receipt of clinical services and/or health outcomes for children who are diagnosed with condition(s) mandated by their State-sponsored newborn screening programs.**

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 receipt of clinical services and/or health outcomes for children who are diagnosed with condition(s) mandated by their State-sponsored newborn screening programs:

**4 of 8 (50%) Heartland states** have systems in place to track receipt of clinical services and/or health outcomes for children who are diagnosed with conditions mandated by their state-sponsored newborn screening programs. Those states are: AR, IA, KS, and OK.

Data Source:

**Heartland NBS Coordinators**

Comments:

**SD:** Currently does not have above system, but is just beginning to establish LTFU tracking system for PKU, CH, and galactosemia.

**NE:** Not at this time, but they know who is receiving clinical treatment and medical foods because they pay for them.

**MO:** Does not have a system currently in use, but they are working on a data linkage system that the clinical treatment centers could access and provide up-to-date clinical information each time the patient is seen.

**ND:** No system to track but is aware of the children seen by the state-sponsored quarterly metabolic clinic.

**Please provide, as an attachment, specific information about the state systems that are in place in your region. If possible, include information about: how long children are tracked; whether the systems include all conditions mandated by the state's NBS program, including hearing screening; which program(s) is responsible for tracking; whether both primary care and specialty (including genetic) services are tracked; and, what, if any health outcomes, are tracked.**

**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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