

**Advisory Board Meeting
Monday, April 13, 2009—2:30-3:30 pm
Summary**

Attendees: Barb Schweitzer (ND), Majed Dasouki (KS), Amy Brower (NE), Lucy Fossen (SD), Jamey Kendall (KS), Julie Miller (NE), Kim Piper (IA), Mary Riske (ND), Larry Weatherford (OK), Sharon Vaz (OK) **Guests:** JoAnn Bolick (AR), Annette Arnold (AR), Barb Jackson (NE), Bev Duffel (SD)

RCC Staff: John Mulvihill, Lori Williamson and Shona Whitehead

Agenda Item	Discussion	Action
Welcome and Attendance		
Review of last meeting summary		Accepted as recorded
FY 09-10 Renewal—Update	<p>New activities include: Nursing education using University of Iowa online modules and metabolic grand rounds via telehealth.</p> <p>Narrative will be posted on website after award announcement is made and any contingencies addressed.</p> <p>Evaluation to be discussed later on call.</p> <p>Several activities will conclude in FY 09-10.</p>	
Funding opportunities	<p>a. HRSA Supplement—HRSA received some extra dollars for the regions. Mulvihill initially responded with our most expensive base-funded projects, but HRSA wanted new activities to be proposed. In less than 24hrs, the HRCC put out a call for information from the state NBS programs and Amy Brower to identify and refine a submission. The key need identified, based on survey of current systems in each state, is data linkage systems for NBS programs. Verbal feedback from HRSA indicates that the proposal looks good to receive funding, but nothing has been sent in writing. Possible notification to be sent this week.</p> <p>b.& c. Stimulus Grants and NBS Saves Lives Act—The NIH will be awarding two hundred (200) \$1 million challenge grants as a part of the stimulus funding. Two conference calls were held in</p>	

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	<p>March to discuss potential ideas for grant submission. Many great ideas were proposed. (A summary of these calls was sent previously). If the HRSA supplement (item a. above) is received, a contingency is to also respond to the forthcoming RFA for NBS Saves Lives grants. The release date for the RFA is unknown. The focus of the proposal and subsequent grant would be LTFU. Because of the overwhelming response to the stimulus challenge grants, it would be a better use of the Collaborative’s time to focus on tailoring a grant proposal to a more specific NBS or genetics focused RFA like the NBS Saves Lives Act grants.</p> <p>d. NBSTRN—National cohort study involving LTFU. Mulvihill has been invited to serve on the planning committee. Committee is meeting later this week in Bethesda. At some point, Heartland states will need to decide if they want to participate.</p> <p>Kim Piper commented that four states (NY, CA, UT and IA) have a CDC grant for a NBS surveillance project that uses LTFU databases. The project is still in its first year.</p>	<p>Kim Piper will send data set to HRCC.</p>
<p>Follow-up of webinar meeting with Cerner</p>	<p>Due to the change in focus from the Stimulus grant to the NBS Save Lives funding, this is no longer applicable.</p> <p>Cerner is developing health information technology products produces for LTFU. HRCC was in contact with their representatives after a suggestion from Amy Brower and because they are headquartered in the Heartland region. Brower also pointed out that Cerner was involved with an American Health Information Community (AHIC) use case for NBS. She also suggested that everyone read the resulting white paper written from the study. http://www.hhs.gov/healthit/usecases/nbs.html</p> <p>Julie Miller asked if there were other companies that have or are developing products for LTFU. Brower responded that there are others.</p> <p>Mulvihill believes that templates in EMR for genetic diseases are needed.</p>	

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<p>DBS Storage/Research Policy Call</p>	<p>A meeting of policy makers and state health representatives was convened by ACMG to discuss DBS storage and research. A portion of the meeting was available via webinar to invited attendees. (In-person invitees were not representative of all the regions.) At least 7 of the 8 Heartland states joined the meeting via webinar</p> <p>Feedback from the participating states:</p> <p>Julie Miller asked during the meeting if funding would be linked to policy changes, and Rodney Howell indicated that it would be linked.</p> <p>It was clear that state policies for DBS storage are variable.</p> <p>There are groups on both sides of this debate—Advocacy groups against government intrusion or privacy advocates and those supportive of the NBSTRN</p> <p>Does Brad Therrall have a data set with all the state policies?</p> <p>Amy Brower asked if we know the policies for just the Heartland states? Yes, previously Sharmini Rogers conducted a survey.</p>	<p>HRCC will request data from Sharmini Rogers’s survey and request permission to distribute it to the Board.</p> <p>Lori Williamson will send slides from meeting webinar to Advisory Board.</p>
<p>Implementation of Evaluation Plan</p>	<p>(Evaluation Plan for FY 09-10 sent in advance of call)</p> <p>Barbara Jackson provided a quick overview of the evaluation plan for the remainder of FY 08-09. She plans to attend the NBS workshop and meet with the Back-up testing project personnel and the 3 states that whoa ve completed the NBS exchange program while in Lincoln, NE. She is providing technical assistance to the pilot project funding recipients.</p> <p>In FY 09-10, the plan is to attend the Annual meeting to conduct focus groups with members of the collaborative. She highlighted specific items included in the plan: metabolic grand rounds, Medhome Portal modules and CME, LEND student projects, family resource guide and the University of Iowa nursing modules.</p>	<p>If you any questions regarding the Heartland Evaluation Plan please contact: Barb Jackson at bjackson@unmc.edu or Lori Williamson at lori-williamson@ouhsc.edu.</p>

Heartland Genetics and Newborn Screening Collaborative

Agenda Item	Discussion	Action
Annual Meeting	Planning committee meets again April 20 th . RFPs are being requested from area hotels. A draft agenda will be sent the Advisory Board after the next planning committee meeting.	
Announcements	Julie Miller commented there has been a flurry of activity and communication from the HRCC that has kept the states/Advisory Board involved.	
Next meeting	Upcoming Meetings: Heartland NBS Workshop--April 30 & May 1—Lincoln, NE GSA Expert Panel Meeting—May 7-8, 2009—Dallas, TX Heartland Annual Meeting—September 16-18—Little Rock, AR	Monday, May 11, 2009