

**Newborn Screening Work Group Meeting
 Wednesday, January 28, 2009
 3:30-4:30 pm**

Attendees: Barb Schweitzer (ND), Julie Miller (NE), Krystal Baumart (NE), Laurie Smith (MO), Leslie Himstedt (AR), Lucy Fossen (SD), Majed Dasouki (KS), Patrick Hopkins (MO), Sharmini Rogers (MO), Amy Brower (NE), Colleen Peterson (KS), Julie Raburn-Miller (MO), Mary Monks (OK), Michael Kayser (OK), Sharon Vaz (OK), Sarah Groenveld (SD) and Annette Arnold (AR)

Staff: Lori Williamson and Shona Whitehead

Meeting Summary:

Agenda Item	Discussion	Action
NBS Exchange Program	<p>A. Reminder to those states that conducted visits in Spring 2008 the 12-month follow-up assessment will need to be done. The assumption was that the PEAS assesement would also be used for the post evaluation. No other evaluation form has been developed.</p> <p>B. The states that have planned for visits this Spring are reminded that the visits must take place before 5/31/09. Julie Miller encourages that planning start now, even if the visit is a couple of month away.</p>	<p>Contact Lori if you need a due date for your post-assessment. Otherwise, turn them into Lori upon timely completion.</p> <p>Please contact Shona at shona-whitehead@ouhsc.edu once visit dates are confirmed and to arrange travel.</p>
<p>MEMSCIS (https://memscis.org/home/)</p>	<p>Background: It was originally developed by a cardiologist in Minnesota to store patient’s medical info so that it could be accessed by the parent in a medical emergency. Region 4 then adopted the program to benefit metabolic patients. Region 4 helped fund enhancements to the website.</p> <p>Heartland is considering a partnership with Region 4 to also use the website. Work Group members are asked to review the website and provide feedback.</p> <p>Several questions were raised:</p> <ul style="list-style-type: none"> • Who does the data entry? • Is it considered research and need IRB approval? • How are HIPAA guidelines followed? • Who maintains the database? • Who is legally responsible for the database management? • What happens if there is a breach of security? • What happens if the parents loose the card with the password? 	<p>Lori Williamson will contact the project coordinator in Region 4 to get answers to the question asked by the Work Group. If you have additional questions please send them to Lori at lori-williamson@ouhsc.edu.</p>

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Data Evaluation	<p>A. NBS video distribution—please review when you sent your state’s videos out and please follow-up with evaluation surveys.</p> <p>B. It was suggested by Teresa Willige that the parent’s use of the laminated cards and letters and the response from ER physicians or other PCP should be evaluated. The question posed to the group is—would this be valuable feedback or worthwhile?</p> <p>Laurie Smith commented that the laminated cards haven’t been widely used since the implementation of electronic medical records (EMR) at Children’s Mercy.</p>	<p>A. Please return completed surveys to Shona at shona-whitehead@ouhsc.edu.</p>
Report from Stan Berberich	<p>Stan Berberich was unavailable for the call</p>	
Report from Patrick Hopkins	<p>Patrick Hopkins suggested that each state take the time to compare other state’s NBS reports and look for areas of improvement or harmonization. Other things to consider when looking at the reports are: what should be included in the comments section; how should comments be worded; what does the customer need or want; and what does the NBS lab need or want?</p> <p>ND, SD and IA all use the same report. AR and OK have similar reports. NE has an additional report for repeat screening that was not distributed to the group. Baumert will send to Hopkins.</p> <p>It was asked if the demographic data has to be similar? Patrick’s response was that it would aid in emergency back-up, help with border babies and tracking of feeding status.</p> <p>Krystal Baumart asked what the feeding status was used for. Sharmini Rogers indicated that in MO the breast feeding program uses the info and Sarah Groenveld indicated that the NBS lab also uses the data.</p> <p>It is understood that not all areas of the NBS reports are possible to harmonize because some data is used in other programs within the state. Krystal Buamart also commented that having the address, not just the name of the physician of record is important.</p>	

Heartland Genetics and Newborn Screening Collaborative

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	Amy Brower suggested that this type of NBS report comparison be provided to the Federal committee since it has a possible link to Electronic Health Records. She also suggested that Michelle Puryear be notified that this review of NBS reports has been conducted.	Once the group is ready for Lori to forward their work to Dr. Puryear, let Lori know. Appropriate credits will be given.
Mayo Clinic MSMS Training	Remaining trainings in FY 09-10 are: 2/9-13/09 and 4/13-17/09. Colleen Peterson (KS) is attending the February course. Arkansas is planning to send someone in April.	Additional trainings in 2009 are available. Please contact Lori at lori-williamson@ouhsc.edu if you are interested in attending.
Mid-Year Work Group Meeting	After discussion with the Advisory Board it was decided that the February 2009 face to face mid-year meeting should be cancelled. It is possible that specific work group meetings could be held in conjunction with other meetings like the NBS Workshop in Lincoln or the GSA meeting in May 2009. Stay tuned.	The February 23-24, 2009 Mid-year Work Group meeting in Kansas City has been cancelled.
NBS Workshop	April 30 and May 1, 2009 in Lincoln, NE. Heartland will reimburse up to 3 people per state to attend (Please notify Lori if you have more than 3 people who like to attend.). A draft agenda will be distributed ASAP. For those who will not be able to attend, specific portions of the meeting maybe available via teleconference.	Please send any agenda ideas to Shona at shona-whitehead@ouhsc.edu by 10:00 am Friday, January 30, 2009
Next meeting	No February Meeting	March 2009 meeting TBD.