

**Advisory Board Meeting
Wednesday, February 8, 2012**

Meeting Summary

Members: JoAnn Bolick (AR), Jackie Whitfield (AR), Holly Johnson (AR), Stan Berberich (IA), Joni Bosch (IA), Kim Piper (IA), Mary Riske (ND), Jeff Hoffman (NE), Julie Luedtke (NE), Sharon Vaz (OK), Amy Brower (SD), and Lucy Fossen (SD) **Guests:** Barb Jackson (NE), Patricia Scott (AR) and Becky Bailey (ND) **HRCC:** Brad Schaefer, Klaas Wierenga, Lori Williamson, and Shona Whitehead

Agenda Item	Discussion	Action
Heartland Implementation of GSA	<p>Kim Piper asked the State Genetics Coordinators how they were working through the GSA tool. She is working on finalizing Iowa’s submission but had questions. Will this info be used to compare the states to each other or more as internal self-assessment? Julie Luedtke commented that it would be useful for self-evaluation, but comparison between states would be hard due to the lack of definition in the metrics. She felt gathering the documentation was burdensome and didn’t submit any documentation with the completed tool. Mary Riske also agreed that collecting documentation was burdensome.</p> <p>Lori said the GSA tool is intended for state use as internal assessment. Ann will use the feedback from the implementation process, specific to the metrics and gathering documents, so that future modifications can be made. Dr Schaefer suggested that each state do what they could with the tool and provide Ann their editorial comments.</p> <p>Lucy Fossen agreed with the previous comments from the SGCs and added that the tool was not well received by the SD Department of Health, due to specific internal policies regarding surveys and data collection. Her supervisors questioned the amount of extra work it would take to complete.</p> <p>JoAnn Bolick commented that she interpreted this implementation as “phase 1,” with potential changes in the next iteration based on the feedback. She emailed Ann several times as she worked to complete it for Arkansas. Julie said she would like to see references for the metrics sources in the next version, similar to PEAS.</p>	

<p>Heartland’s Competitive Renewal Application</p>	<p>The HRCC team submitted the application. Strategic planning process was extremely helpful in the development of the 5-year plan. The responsiveness of the Advisory Board and other work groups was commendable; given the very short turn-around time give to review various sections of the plan. Mary Riske and Kim Piper both commented the plan looks very good.</p> <p>A few areas were modified from the last discussion with the Advisory Board: EMR, Pilot Projects and GSA. Amy Brower suggested that the HRCC see if any national measures tie in with GSA. Barb Jackson commented that many of the national measures are at the patient/client level, whereas Heartland projects are at the systems level. Lori and Barb will work to develop more region specific measures, where applicable.</p> <p>Julie Luedtke said that the HRCC took a nice approach in including stakeholder input and feedback throughout.</p>	<p>.</p>
<p>2012 Heartland Annual Meeting</p>	<p>Meeting Location: St. Louis, MO Meeting Date: October 3-5, 2012</p>	<p>The HRCC will send out a save the date and a request for volunteers to serve on the planning committee.</p>
<p>SACHDNC report</p>	<p>Please see Klaas Wierenga’s notes that were attached to the meeting announcement. His notes are not official notes, those will be posted along with selected speaker presentations online at: http://www.hrsa.gov/advisorycommittees/mchbadvisory/heritabledisorders/</p>	
<p>Heartland Website</p>	<p>Shona Whitehead announced that the Heartland website is undergoing a make-over to update the overall “look” and make it more up-to-date. Major content changes are not being made at this time. Once the new website is launched, Shona will follow-up with the State Genetics Coordinators to confirm that state specific information is current.</p>	
<p>State Legislative updates</p>	<p>Nebraska—Genetic Counselor Licensure has move forward to “general file”, but needs to a state senator to identify the bill as a priority to help it move more quickly through the system. Lori Williamson offered for the HRCC to provide a letter of support for the bill if that would help.</p> <p>Oklahoma—Sharon Vaz submitted fiscal impact statements for an Adult Sickle Cell Treatment Program and an Umbilical Cord Blood Storage Program coordinating thorough OSDH.</p>	

Heartland Genetics and Newborn Screening Collaborative

Other	Amy Brower commented that the NCC is still waiting to receive the guidance from HRSA for the next funding cycle, so they are moving to wrap up activities by May 31, 2011.	
Next Meetings		March 14, 2012--2:00 pm April 11, 2012 --2:00 pm May 9, 2012-- 2:00 pm