



**Priority 2 Workgroup Telemeeting**  
Notes ~ Friday, December 18, 2009 @ 2 pm ET/1 pm CT

<b>Co-leads:</b> Carolyn Anderson, Susan Berry	<b>Facilitator:</b> Sally J. Hiner, Region 4 Genetics Collaborative Senior Project Coordinator
<b>Participating:</b> Barbara Burton, Loren Pena, IL; Kathy Wood, IN; Jan Askren, KY; Jerry Feldman, MI; Carolyn Anderson, Kristi Bentler, Susan Berry, Anne Jurek, MN; Bill Rhead, WI; Jill Skrabel, NE; Jill Shugar, HRSA; Sally Hiner, R4.	
<b>Meeting Goals:</b>	
<ul style="list-style-type: none"> <li>• <b>Workgroup will continue efforts to develop and implement IBEM-IS</b></li> <li>• <b>Workgroup will be informed of national and cross regional collaboration activities</b></li> </ul>	

Item	Discussion/Notes	Recommendation/Action	Follow up (who/when)
I. Roll Call – Berry conducted roll call, introductions and welcome.			
II. IBEM-IS Updates			
A. Data Collection Report	The monthly report, provided prior to the meeting, was reviewed and discussed. Berry noted there has not been much change in numbers since the last report.		
B. Problems/Issues	Berry reported issues with permissions had been identified. Berry and Hiner tele-met with Julia Nash (Doc Site) and assigning of permissions was clarified. The glitch was within the Doc Site system, not our process.		
C. Other	IN received a HRSA IT grant for long-term follow-up. Berry learned from Bob Bowman (IN) that, because of this project to link their state data systems, they are exploring how the IBEM-IS also can be linked in. IN has examined all of the Priority 2 disease surveys to see what elements would be of interest in surveillance. Bob will be sharing the report with Sue.	The IN report may be a useful tool as we work to strengthen involvement of our state partners in the IBEM-IS.	Sue to share report with workgroup
III. National and Cross-Regional Collaboration			
A. Update – NBSCTRN Standing Committee	This group met recently and engaged in a review of what the network is to be addressing. On a national basis, there is a need to move forward with developing the disease specific elements not included in initial development by the Long-term Follow Up Committee (a sub-committee of the Secretary’s Advisory Group). It continues to look like		

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	the result will be a combination of the work this group (P2) has done and that done by the Mountain States Regional Collaborative.		
B. Surveillance and Research	Anderson reported that MN is creating a dataset that has both surveillance and research elements. She is working to get input from states concerning how interested they are in 1) obtaining surveillance data in general and 2) the possibility of using the IBEM-IS to obtain the data. Indiana and Missouri are interested.	Need to develop a plan and a timeline for moving forward with this activity. It will become an important part of our data.	
<b>IV. Face-to-face Meeting (11.20.09) Highlights</b>			
A. Going National	The Priority projects will change at the end of the five years – likely will not be within the region.	The group agreed to forge ahead anyway; perhaps we will help influence the national model.	
B. Terms of Engagement in Research and Data Sharing	Mike Watson, NCC is working to organize a meeting to bring together some founding principles for data sharing and use as the national database evolves.	If anyone is interested in participating in the national discussion, please let Sue know and she will provide the names to Mike for consideration.	Interested Workgroup members to contact Sue as soon as possible.
C. Reports	We need feedback to set up reports in menus that are more user-friendly and more pertinent than those which currently can be created with the report wizard.	Needs to be a topic for discussion on future agendas.	Co-leads, Hiner
D. Certificate of Confidentiality	The group discussed the potential benefits of obtaining a CoC.	Needs to be further explored.	Co-leads, Hiner

Notes by Hiner