



## Rochester Epidemiology Project Community Advisory Board Meeting Notes October 4, 2012

**In attendance - CAB Members:** Helena Abrom, Chris Burdick, Marie Cano, Ken Caron, John Doyle, Aundrea Douglas, Joanne Ericksen, Leo Evans, Mary Lamprecht, Laura Mix, Liz Morice, Dee Servick, John Tierney, David Trester, Vad Try, Dennis Uthke, Brent Westra, and Sonia Winslett

**In attendance – REP Team:** Barbara Yawn, Barbara Koenig, Walter Rocca, Jennifer St. Sauver, and Lori Klein

The meeting began with introductions and a review of the materials to be added to the binders.

- REP Deliberation Community Engagement slideshow
- Data Protection Practices slideshow
- Health Information Privacy slideshow
- REP Research Process Flow Charts
- Study Flow Chart
- Manuscript - History of the Rochester Epidemiology Project: Half a century of medical records linkage in a United States population
- Post Bulletin articles about the REP

Barbara Koenig reviewed the slides “REP Deliberative Community Engagement” Presentation for CAB (included in member binders). The slides provided a recap of the community event held in the fall of 2011 from which the idea of a CAB was generated. Barbara K. also encouraged the group to begin thinking about volunteering for a leadership role within the CAB as the Co-Chairperson. The Co-Chair position will be discussed in more detail at the next meeting (January 24, 2012).

Gail Onderak, Biobank CAB Co-Chairperson, shared her experiences as a CAB member and leader. Gail attended the Biobank community deliberative engagement event and along with ½ of the other participants eventually joined together to form the community advisory board. As the Co-Chair she provides input and coordination for meeting agendas and attends Mayo Clinic Biobank related leadership meetings as necessary. Gail expressed to the group the important role CAB members play because each member has an opportunity to be a voice for the community and study participants. Gail also mentioned a book she and other members of the Biobank CAB read together – the book title is “The Immortal Life of Henrietta Lacks” and was written by Rebecca Skloot.

Barbara Yawn reviewed the Study Flow Chart (included in member binders). The flow chart follows the process of a study from idea to publication. The CAB members expressed questions about how the study information is disseminated to the general public. After discussing the

current methods for publicizing study information, Dr. Yawn told the group that one of the future tasks of the CAB would be to generate ideas for the best way to publicize this information to the community.

- Gail mentioned that the Biobank CAB sends out a newsletter to all Biobank study participants and perhaps the REP could consider a similar method to highlight REP studies.

The final discussion was about future meetings. CAB members will provide input on structure, timing, and content of future meetings.

- Example: Gail shared that the first several meetings of the Biobank CAB were primarily educational so that members fully understood the Biobank. Now the group meets every other month. Their meeting format includes broad discussions along with small group discussions with report-back to the full group. There is no formal vote on decision making, but rather prioritization based on consensus.

There was agreement from the group to hold the next meeting in January or February (scheduled for January 24, 2013) and would include a tour of the Olmsted Medical Center (OMC) Research Office with meeting and dinner to follow at the OMC Clinic. CAB members requested the following topics of discussion:

- Review in detail the process of a REP research request
  - Review the slides “REP Research Process Flow Chart” (included in member binders)
- What happens if a REP study discovers something negative? Such as an experimental drug hurts people rather than helps? How is it handled?
- Review the results of the deliberative community engagement & prioritize CAB activities:
  - Privacy & confidentiality
  - REP study recruitment procedures
  - Communication strategy
  - Community role in REP governance
- Discuss the role of CAB members and the Co-Chair position