



Rochester Epidemiology Project Community Advisory Board Meeting Notes January 24, 2013

In attendance - Board Members: Helena Abrom, Chris Burdick, Marie Cano, Ken Caron, John Doyle, Aundrea Douglas, Joanne Ericksen, 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, Lila Rutten, and Lori Klein

The meeting began with a tour of the Olmsted Medical Center Research Office. During the tour, security procedures regarding entrance, file storage, and data access were reviewed.

Following the tour, the meeting resumed at Olmsted Medical Center Clinic. The following items were reviewed as additions to the informational binders:

- Deliberative outputs summary
- Co-chair job description
- Published paper: *Why patients visit their doctors: Assessing the most prevalent conditions in a defined American population*
- Excerpt from published paper: *Gulf War and Health*
- Published paper: *Attention-deficit/hyperactivity disorder after early exposure to procedures requiring general anesthesia*
- Poster: *Engaging the public in governing population-based medical records research*
- “REP in the news” articles

After a brief review of the deliberative outputs (1. privacy and confidentiality; 2. communication strategy; 3. REP study recruitment procedures; and 4. community role in REP governance), a brainstorming session was facilitated. The majority of the discussion focused on communication strategy and the following ideas were identified:

- Recruit/inform at county fairs
- Educate local employers
- CAB members staff booths
- Salvation Army – educate so that they understand (and other new sites, such as Hawthorne)
- PAlIR – Rochester
- Adult and Community Education organizations; RCTC Clinic
- Commercials on public radio, TV
- Newspaper advertising, articles
- Booth at local Health Fairs (already at Rochester Women’s Expo)
- Project Community Connect

- Twitter, Facebook, blogs
- School systems - annual STEM event
- School systems in Rochester and surrounding communities
- Faith-based organizations
- Parish nursing
- Public Health Department – sends health bulletins that are used by churches
- Booth at Gay Pride event
- Hormel Institute
- Mayo Clinic & Olmsted Medical Center media services to publicize REP research locally (already happening)
- Fine arts community and theatre (may be resource for assisting with design of materials)
- Senior Citizen Centers
- Public Library
- Booth in the skyway/food court during lunch time
- Chamber of Commerce/business community in Rochester and surrounding communities
- Work Force Center
- Public access television station (Jane Belau); special language stations
- IMAA (Intercultural Mutual Assistance Association)
- United Way
- Link on REP website explaining how you can be “in” or “out” of REP; query regarding status of in or out; maybe send research authorization forms or add to Mayo patient portal apps
- Email (from doc/system, patient portal)
- Sports organizations and venues
- Targeted ads, such as parents of new babies (Ex: Baby’s R Us registry; welcome packet from post office for new residents)
- Target college-aged students regarding age 18 reauthorization; provide information
- Volunteer at local telethons or set-up booth at telethon
- Booth for “Research Day”
- Diversity council, minority liaison in schools
- Catholic Charities, Lutheran Social Services
- Add RSS feeds for people who have signed up
- Interpreter services at Mayo Clinic and OMC
- Use Dr. St. Sauver’s paper about why people go to the doctor to help educate front line workers about importance of REP and research

In addition to the ideas generated during the brainstorming session, a separate list of general questions was tabled for future discussion using the “parking lot” method of recording. The items on the “parking lot” list include:

- Should the group consider renaming the community advisory board?
- Why no camera near computers (only near doors) at OMC Research Office?
- Concern about there being no blind on the window in the back room of Research Office
- Concern about searching by name and gaining access to clinic number
- What is the process for employee sign out when no longer an employee?
- What is the procedure for new employees to learn the process?

Barbara Yawn reviewed the job description for the co-chair position and reminded members that an election will be held during the next meeting. The elected co-chair will be encouraged to attend REP-related meetings occasionally throughout the year and will be reimbursed for attendance and parking as applicable. Board members interested in the co-chair role should compose a reply to the question “why I want to co-chair the community advisory board of the Rochester Epidemiology Project” and plan to present the response to the group during the April meeting. A secret ballot election will follow.

In response to questions posed at the October meeting regarding the benefits of research, Walter Rocca presented three examples of noteworthy research studies and the pivotal role of the REP in relation to the studies. A copy of all three study examples were included in the handout of items to be added to the binders.

There was agreement from the group to hold the next meeting in approximately three months (**scheduled for April 25, 2013**). Discussion topics include:

- Co-chair election
- Prioritize ideas related to communication strategy
- Address parking lot items
- Private website for community advisory board