



Rochester Epidemiology Project Deliberative Community Engagement Summary to guide 1/24/13 discussion

In the fall of 2011 an extensive 4 day community engagement was held over 2 weekends. It was professionally facilitated with a diverse group of participants from the community. A summary of deliberation outcomes was mailed to all participants. In March of 2012 the REP leadership responded to the community members. The CAB was formed. (See the full version of Deliberative Community Engagement documents in your binder under the tab "REP Info.")

COMMUNITY HOPES EXPRESSED

1. Transparency through educating/communicating with the community
2. Continued use and growth of the REP
3. Community involvement with the REP

COMMUNITY CONCERNS

1. Data safety, misuse, and privacy
2. Need for refinements in the research authorization process
3. Need for community education
4. Efficiency (REP should remain useful for researchers)

DELIBERATIVE OUTPUTS FOR DISCUSSION

1. PRIVACY AND CONFIDENTIALITY

Recommendation: Deliberants felt that the REP needs to provide better education about the research authorization law to people living in Olmsted County and southeastern Minnesota.

Recommendation: Most deliberants suggested that information about the REP should accompany the research authorization forms.

Recommendation: Some deliberants felt that it is incorrect to include people in the REP who do not actually sign a research authorization form. It may be legal, but it may not be ethical. Other deliberants felt that the current process is fine.

Recommendation: Some deliberants suggested regularly re-authorizing REP participants, since peoples' minds often change over time. However, others thought that the REP should not do so since the current system already allows people to change their mind at any time. Furthermore, regular re-authorization may have negative implications for research (by draining funds and resources).

2. COMMUNICATION STRATEGY

Recommendation: Deliberants clearly expressed the hope that the REP would improve communication to the Olmsted County community and other communities as the REP expansion occurs.

Recommendation: Many deliberants felt that front-line healthcare workers should know more about the REP since this would be part of educating the community (this has started at OMC).

3. REP STUDY RECRUITMENT PROCEDURES

- Discussion deferred

4. COMMUNITY ROLE IN REP GOVERNANCE

Recommendation: All deliberants felt the REP should create a group that includes community members. (Need to refine and define role.)