



What's Next: Advancing CBPR and Ethical Considerations

**Conference Call Series on Institutional Review Boards
and Ethical Issues in Research**

Co-sponsored by

*Community-Campus Partnerships for Health & Tuskegee University National
Center for Bioethics in Research and Health Care*

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Sarah Beversdorf, MPH/MSW

Syed Ahmed, MD, MPH, DrPH

Story Session

- U.S. conference presentation of a community-academic partnership IRB experience – May 2006
 - Approximately 30 attendees
 - Representatives from both communities and academia
 - Story was shared in a ‘traditional’ (eg, Once Upon A Time) manner

Story Session

- Brainstorming on 3 post-story questions
 - What are IRB/REB* strategies that respect the law, protect communities, and appreciate the community context?
 - What are strategies that engage communities in IRB/REB-related discussions and increase the understanding of IRB/REB systems?
 - What role can a national community-academic partnership organization play in advancing these efforts?

* REB=Research Ethics Board (Canada)

Story Session

- Results were published in the conference proceedings*
 - Some editing of story and responses (eg, responses are not verbatim)
 - Some editing of questions (reframing for better articulation; IRB/REB)
 - Added references that affirmed attendees' responses

* Beversdorf, S., Ahmed, S., & Beck, B. (2007). Community-Academic Partnerships and Institutional Review Board Insights. Partnership Perspectives, IV, Issue I, 95-104. Available at <http://ccph.info/>.

Results

- What are IRB/REB strategies that respect the law, protect communities, and appreciate the community context?
 - Increase the level of communication with the IRB/REB through:
 - Community-based researchers developing strong relationships with IRB/REB staff
 - Community-based researchers becoming a member of the IRB/REB
 - Community-based researchers holding annual or regular meetings with IRB/REB members and staff (share models, examples of hindrances, discuss scope of IRB/REB)

Results

- What are IRB/REB strategies that respect the law, protect communities, and appreciate the community context? (cont'd)
 - Consider arrangements for IRBs/REBs sharing power or leadership when multiple IRBs/REBs are involved in one study
 - Academicians can create an 'umbrella protocol' that allows some community-based efforts to move forward, with place holders for future efforts (and presumably faster review)
 - On national level panels, community-based researchers can raise issues surrounding community-based research and IRBs/REBs

Additional Possibilities

- What are IRB/REB strategies that respect the law, protect communities, and appreciate the community context?
 - Have basic training for IRBs/REBs engaged in CBPR (Flicker, et al, 2007*)
 - Increase IRB/REB requirements for documenting CBPR decision-making (Flicker, et al, 2007)
 - Develop IRB/REB requirements for partnership/relationship memoranda of understanding (Flicker, et al, 2007)

* Flicker, S., Travers, R., Guta, A., McDonald, S., Meagher, A. (2007). Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards. Journal of Urban Health **e-pub** (DOI 10.1007/s11524-007-9165-7).

Additional Possibilities

- What are IRB/REB strategies that respect the law, protect communities, and appreciate the community context?
 - Assure that at least one IRB/REB member is knowledgeable on CBPR issues (CCPH Interest Group, 2007*)
 - Assure that IRBs/REBs require community input documentation (CCPH Interest Group, 2007)
 - Encourage IRB/REB transparency (eg, availability of names, expertise areas, staff to contact, etc.) (CCPH Interest Group, 2007)
 - IRBs/REBs develop specific CBPR criteria (CCPH Interest Group, 2007)

* Attendees at the 'Ethical Issues in Community-Academic Partnerships' Interest Group at the CCPH 10th Anniversary Conference, April 12-14, 2007. Toronto, Canada.

Results

- What are strategies that engage communities in IRB/REB-related discussions and increase the understanding of IRB/REB systems?
 - Create materials that describe research and research responsibilities and requirements
 - Create materials or hold trainings on:
 - How communities can benefit from IRBs/REBs
 - What is the history behind IRBs/REBs (makes it real)
 - Promotion and tenure in academic institutions
 - Benefits of research
 - Informed consent and its significance

Results

- What are strategies that engage communities in IRB/REB-related discussions and increase the understanding of IRB/REB systems? (cont'd)
 - Dialogue with the community about the community's history and future with research
 - Encourage community member representation on IRBs/REBs
 - Have a community IRB/REB or another community approval process

Additional Possibilities

- What are strategies that engage communities in IRB/REB-related discussions and increase the understanding of IRB/REB systems?
 - Survey communities in the US and Canada to identify elements of community IRBs/REBs (CCPH Interest Group, 2007)
 - Develop a set of community-based research ethics (CCPH Interest Group, 2007)
 - Develop a checklist for community members to know what to ask researchers (CCPH Interest Group, 2007)
 - Redefine Belmont Report ethical concepts to include community perceptions/understandings/definitions (CCPH Interest Group, 2007)

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Additional Possibilities

- What are strategies that engage communities in IRB/REB-related discussions and increase the understanding of IRB/REB systems?
 - Develop incentives/rewards for community members on IRBs/REBs (CCPH Interest Group, 2007)
 - Develop a community consent process (CCPH Interest Group, 2007)
 - Convene community gatherings to identify community research priorities (CCPH Interest Group, 2007)

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Results

- What role can a national community-academic partnership organization (ie, CCPH) play in advancing these efforts?
 - Education
 - Develop educational materials that could be shared with IRBs/REBs
 - Develop educational materials or a toolkit that could be shared with researchers or community members, potentially including information on:
 - What is research?
 - What questions should communities be asking?
 - What is the IRB/REB and why is it so stringent?
 - How can communities and academia work together to successfully and satisfactorily accomplish research?
 - What other resources are available?

Results

- What role can a national community-academic partnership organization (ie, CCPH) play in advancing these efforts? (cont'd)
 - Technical assistance
 - Be a resource for trouble-shooting support
 - Have a clearinghouse for successful community-based IRB/REB protocols
 - Develop a model for a community research board
 - Develop a framework for community advisory boards
 - Develop a sample/template consent form that is at the 6th grade reading level

Conclusions

- Protection of individuals and communities during research is critical.
- Information and dialogue that increases mutual understanding of communities and academia (particularly the IRBs/REBs) are essential to full protection of individuals in communities.
- CCPH and others have the opportunity to move this agenda forward!

Citations

- Beversdorf, S., Ahmed, S., & Beck, B. (2007). Community-Academic Partnerships and Institutional Review Board Insights. Partnership Perspectives, IV, Issue I, 95-104.
- Flicker, S., Travers, R., Guta, A., McDonald, S., Meagher, A. (2007). Ethical Dilemmas in Community-Based Participatory Research: Recommendations for Institutional Review Boards. Journal of Urban Health, e-pub (DOI 10.1007/s11524-007-9165-7).
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