What’s Next: Advancing CBPR and Ethical Considerations

Conference Call Series on Institutional Review Boards and Ethical Issues in Research
Co-sponsored by
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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

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)

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 (e.g., availability of names, expertise areas, staff to contact, etc.) (CCPH Interest Group, 2007)
  - IRBs/REBs develop specific CBPR criteria (CCPH Interest Group, 2007)

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)

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)

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

