



# Understanding Community-Based Processes for Research Ethics Review

- **Nancy Shore, University of New England (UNE)**
- **Sarena D. Seifer, Community-Campus Partnerships for Health (CCPH)**
- **Kristine Wong, CCPH**
- **Ruta Bajorunaite, Medical College of Wisconsin**
- **Lisa Moy, CCPH**
- **Kirsten Cyr, UNE**
- **Andrea Corage Baden, CCPH**

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# Background

- Increasing recognition of the importance of engaging communities to address health disparities
- Increasing recognition of the challenges community-engaged researchers may encounter with institution-based IRBs
- Increasing number of community groups and community-institutional partnerships developing review processes

# Study Aims

- To identify and describe the types of processes and protocols that community groups and community-institutional partnerships use to assess whether to participate in or support a research study.
- To assess the similarities and differences between the protocols used by community-based processes for research ethics review and those used by institution-based IRBs.

# Constructing the sample

- Extensive search for community groups and community-institutional partnerships conducting, participating in, or reviewing research
  - Bibliographic and funding databases
  - Online program conference agendas
  - OHRP and Indian Health Service IRB databases
- Posted study information to relevant list serves

# Respondents with a community-based process for research ethics review (n=109)

Community-institutional partnership	34 (31%)
Community-based organization	24 (22%)
Community health center	13 (12%)
Non-profit organization	13 (12%)
Tribal organization	8 (7%)
Other (e.g., coalition, K-12 school)	17 (16 %)

# Reasons for establishing a research review process (n=109)

To make sure the community directly benefits	93 (85%)
To make sure the community is engaged	82 (75%)
To protect our community from possible risk	74 (68%)
To respond to a growing number of researchers asking us to support/participate in their research	45 (41%)
To set our own research agenda	18 (17%)

- *To assist in establishing equity in the decision-making process*
- *To ensure that research is consistent with our institutional mission, [that it] can reasonably be integrated into current functions, and to ensure that leadership and resources are available to effectively support proposed research*

# Benefits of having a review process

- Ensure that the research conducted is relevant, feasible and “done the right way”
- Assure community benefit and minimize risks
- Allow for greater community voice in determining which projects are approved
- Create opportunities for capacity building

*“Exposes community members to the research process and enterprise to help develop their expertise and knowledge about health issues and disparities in health”*

*“Helps us to focus on research being done the right way, rather than getting steered into projects that seem like a lot of resources, but ultimately ends up hurting the community due to improper research methodology”*

# Research ethics review considerations (n=109)

Consideration	Mean (SD)
Research methods that are appropriate to the community	2.95 (0.21)
Good fit with the community's agenda	2.87 (0.34)
Culturally appropriate recruitment strategies	2.87 (0.41)
Plans to share findings with the communities involved in the research	2.87 (0.36)
Culturally appropriate informed consent	2.86 (0.40)
Community-level risks and benefits	2.85 (0.30)
Community consent	2.85 (0.30)

# Concerns identified through the review process

- Inadequate community engagement
- Concerns regarding:
  - community relevance and benefits
  - researchers' cultural competence
  - proposed study not feasible
  - potential burden to the involved community
- Lack of:
  - specification of data ownership
  - plans to report findings back to the community

# Percentage of proposals also reviewed by an institution-based IRB (n=109)

None	9 (8%)
1-24%	23 (21%)
25-49%	5 (5%)
50-74%	6 (6%)
75-99%	13 (12%)
All	53 (49%)

# **Main reasons for proposals also being submitted to an Institution- based IRB (n=100)**

- Involvement of university researchers 82(82%)
- Funders require it 58 (58%)
- Provides an added layer of protection 47 (47%)

# Study limitations

- Sample construction
- Challenges with the online survey
- Limits with survey responses

# Next steps

- Subsequent phases
  - Form a collaborative research network with interested survey respondents
  - Partner with groups to conduct an in-depth cross-case study analysis of their research ethics review processes
- Envisioned benefits
  - Support others engaged in community-based research in developing or strengthening their own review process
  - Support institution-based IRBs in their efforts to better respond to community-based research

For updates on study findings, email [cbresearch@une.edu](mailto:cbresearch@une.edu)

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  - National Association of Community Health Centers
  - National Health Care for the Homeless Council
  - Public Responsibility in Medicine and Research
  - Tuskegee University National Center for Bioethics in Research and Health Care



# Tap into Resources!

[www.ccph.info](http://www.ccph.info)

- Online reports & toolkits
  - Ensuring Community-Level Research Protections
  - Developing & Sustaining CBPR Partnerships
- Electronic discussion groups
  - CBPR
  - Ethics & CBPR
- Communities as Partners in Cancer Clinical Trials: Funds to implement IRB recommendations – [Dec 5 deadline](#)