



Belmont Report: Working with Communities

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Interpretation of the Belmont Principles: Respect for Persons

- Valuing the different experiences within the research partnership
- Creating a participatory process where all partners have a voice in decision-making
- Translating findings into actual community benefits
- Acknowledging multiple meanings of respect
- Accounting for community-level consent

Interpretation of the Belmont Principles: Beneficence

- Strengthening the community's ability to address identified concerns
 - Leveraging resources
 - Building capacity
- Translating findings into action
 - *“If our research does not help the community organizations that we're working with improve the condition that brought them to us, then we haven't done our jobs...”*

-Shore (2006)

Interpretation of the Belmont Principles: Justice

- Creating an equitable research partnership
- Challenging unjust structural problems
 - *“Justice really is not about helping people; it is about changing the social conditions that cause them to need help to begin with”*

-Shore (2006)

Does the Belmont Report provide guidance for working with communities?

- “...community should play a role in determining what counts as a risk posed by research, a benefit of research, and an appropriate balance between the two” (Chen et al., 2006, p. S1-125)
- “For the investigator, it is a means to examine whether the proposed research is properly designed. For a review committee, it is a method for determining whether risks that will be presented to subjects are justified. For prospective subjects, the assessment will assist the determination whether or not to participate” (Belmont Report, 1979)



Understanding Community-Based Processes for Research Ethics Review

CCPH & University of New England (UNE)

Funded by Greenwall Foundation

- *Aim:* To identify and describe community-based mechanisms for research ethics review through an online survey of U.S. community groups and community-institutional partnerships involved in human subjects research
- *Study team:*
 - CCPH: Sarena Seifer, Kristine Wong, Lisa Moy, Andrea Corage-Baden
 - Medical College of Wisconsin: Ruta Brazuaskas, Elaine Drew
 - UNE: Nancy Shore, Kirsten Cyr, Jocelyn Ulevicus
- *Study advisory committee:* next slide

Study Advisory Committee

- **Bonnie Duran**, Indigenous Wellness Research Institute, University of WA
- **Sarah Flicker**, York University
- **Bill Freeman**, Northwest Indian College
- **Kelly Edwards**, Dept. of Medical Ethics, University of WA
- **Helen McGough**, Retired IRB Administrator, University of WA
- **Ann-Gel Palermo**, Harlem Community and Academic Partnership
- **Michelle Proser**, National Association of Community Health Centers
- **Joan Sieber**, Journal of Empirical Research on Human Research Ethics
- **Linda Silka**, Policy Research Center, University of ME
- **Stephen Sodeke**, Tuskegee Bioethics Center
- **Eric Wat**, Special Services for Groups

Study Participants

- 172 respondents who met study criteria
 - 109 respondents with a review process
 - 30 respondents planning to establish a process
 - 33 respondents with no plans for establishing a process

Types of Research Reviewed

(n=109)

Research Approach	N (%)
Community-based Participatory Research	95 (87%)
Social and Behavioral Research	60 (55%)
Health Services Research	52 (48%)
Clinical Research	39 (36%)
Quality Improvement	36 (33%)

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

Reasons	N (%)
To make sure the community directly benefits	93 (85%)
To make sure the community is engaged	82 (75%)
To protect our community from possible risks	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%)
Other	23 (21 %)

Factors considered “very important” when reviewing research proposals (n=109)

	N (%)
Research methods are appropriate to the community	104 (95%)
Culturally appropriate recruitment strategies	98 (90%)
Plans to share findings with communities involved in research	96 (88%)
Culturally appropriate individual informed consent	96 (88%)
Good fit with community’s agenda	95 (87%)
Community-level risks and benefits	94 (86%)
Community consent	94 (86%)
Shared power & resources among partners involved in research	85 (78%)
Plans to translate research findings into practice or policy changes	85 (78%)
Opportunities for community training or capacity building	82 (75%)

Benefits of having a review process

- Ensure that the research conducted is relevant or beneficial to the involved community/organization
- 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*

University-based IRB forms

- Is there a section on staff training and/or community capacity-building? • 0/30
- Do the forms ask about commitment to action and follow-up based on results? • 2/30
- Do the forms ask about risks and benefits on a community/societal level? • 4/30
- Do the forms ask about how the research results will be disseminated? • 5/30

Flicker et al. (2007)

Belmont Report and working with communities



Achieving the Promise of Community-Engaged Health Disparities Research: A National Community Partner Forum



Forum Guiding Questions

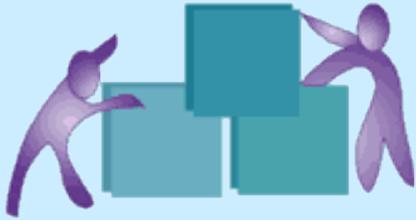
1. How do we ensure that communities most affected by health disparities have a voice at the tables that decide what research gets conducted, how and by whom?
2. How do we support communities most affected by health disparities to conduct and manage their own research?
3. How do we ensure that communities work as equal partners with universities and other institutions to make sure that community research interests are met?
4. How do we ensure that social justice is central to community-engaged research?
5. How do we form effective networks for furthering dialogue and action around community knowledge development and equitable community-academic partnerships?

Forum Planning Committee

- Willie Mae Bennett-Fripp, Exec. Director, Committee for Boston Public Housing, Boston, MA
- Grace Damio, Director of Research and Service Initiatives, Hispanic Health Council, Hartford, CT
- Elmer Freeman, Exec. Director, CCHERS, Boston, MA
- Susan Gust, Community Activist, Minneapolis, MN
- Loretta Jones, Founder & CEO, Healthy African American Families, Los Angeles, CA
- Alma Knows His Gun McCormick, Exec. Director, Messengers for Health, Hardin, MT
- Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership, New York, NY
- Fernando Pineda-Reyes, Exec. Director, Community, Research, Education & Awareness (CREA) Results, Denver, CO
- Alex Pirie, Coordinator, Immigrant Service Providers Group/Health, c/o Somerville Community Corporation, Somerville, MA
- Jean Schensul, Senior Scientist & Founding Director, Institute for Community Research, Hartford, CT
- Peggy Shepard, Exec. Director, WE-ACT for Environmental Justice, New York, NY
- Eric Wat, Director, Research and Evaluation Unit, Special Service for Groups, Los Angeles, CA

Community IRBs & Community Review Boards: Celebrating Successes, Identifying Promising Practices and Addressing Challenges

- What recommendations do we have to offer communities and community organizations regarding why and how to develop and sustain a community-based research review process?
 - Participants:
 - Community IRBs: Hispanic Health Council, North Carolina Commission of Indian Affairs, Papa Ola Lokahi, Special Services for Groups
 - Community Research Review Boards/Committees: Bronx Health Link, Center for Community Health Education Research and Service, Center for Health Equity's Community Research Advisory Board, Galveston Island Community Research Advisory Committee, West Harlem Environmental Action

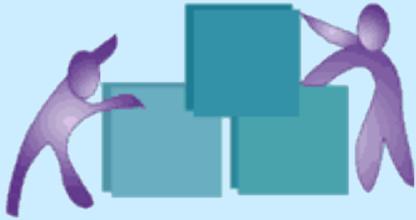


Community-Campus Partnerships for Health

Transforming Communities & Higher Education

To promote health (broadly defined) through partnerships between communities & higher educational institutions





Community-Campus Partnerships for Health

Transforming Communities & Higher Education

- **Mobilize knowledge, wisdom & experience** in communities and in academic institutions to solve pressing health, social, environmental & economic challenges
- **Build capacity** of communities & higher educational institutions to engage each other in authentic partnerships that balance power, share resources & work towards systems change
- **Ensure community-driven social change** is central to the work of community-academic partnerships



Tap into Resources!

www.ccpb.info

Upcoming Events

.CCPB 15th Anniversary Conference, Apr 18-21, 2012 in Houston

Online Reports & Toolkits

.Ensuring Community-Level Research Protections

.Developing & Sustaining CBPR Partnerships

.IRB Curriculum on Community-Engaged Research (forthcoming)

Outlets for Peer-Reviewed Publication

.CES4Health.info

Electronic Discussion Groups

.CBPR, CBPR ethics, Community partners

Selected Citations

1. Chen, D., Jones, L., & Gelberg, L. (2006). Ethics of clinical research within a community-academic partnered participatory framework. *Ethnicity & Disease, 16*, S1-118-135.
2. 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, 84*(4), 469-471.
3. Office of the Secretary (1979). *The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research*. Available at: <http://ohsr.od.nih.gov/guidelines/belmont.html#gob2>.
4. Ross, L., Loup, A., Nelson, R., Botkin, J., Kost, R., Smith, G., & Gehlert, S. (2010). Human subjects protections in community-engaged research: A research ethics framework. *Journal of Empirical Research on Human Research Ethics, 5*(1), 5-18.
5. Shore, N. (2006). Re-conceptualizing the Belmont Report: A community-based participatory research perspective. *Journal of Community Practice, 14*(4), 5-26.
6. Shore, N., Drew, E., Brazuaskas, R. & Seifer, S.D. (2011). Relationships between community-based processes for research ethics review and institution-based IRBs: A national study. *Journal of Empirical Research on Human Research Ethics, 6*(2), 13-21.
7. Shore, N., Brazuaskas, R., Drew, E., Wong, K.A., Moy, L., Baden, A.C., Cyr, K., Ulevicus, J. & Seifer, S.D. (2011). Understanding community-based processes for research ethics review: A national study. *American Journal of Public Health, 101*(S1), S359-364.