



Deciding What Research Takes Place in their Communities: The Role of Community-Based Research Review

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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

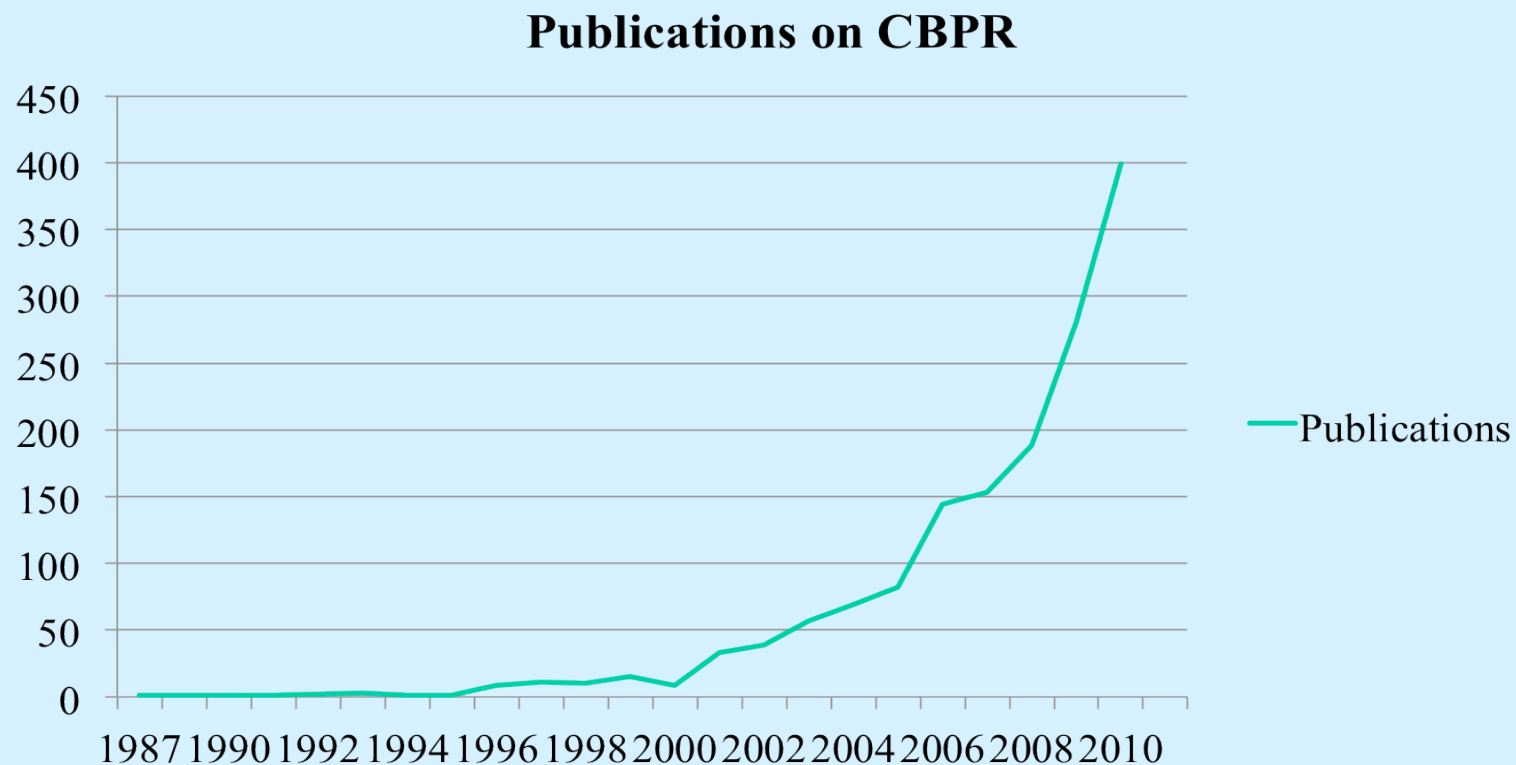
What is CBPR?

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. Community-based participatory research begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change...”

W.K. Kellogg Foundation, 2001

Why a Focus on Ethics Review of CBPR?

CBPR as an approach to research is growing dramatically

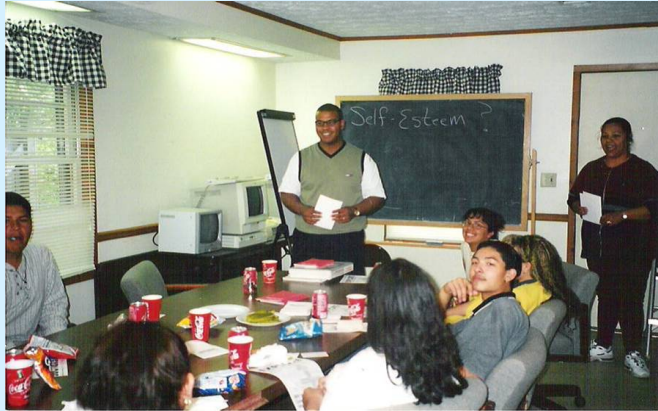


Larry Green, based on unpublished Scopus review by Doug Brugge, 2011.

Why a Focus on Ethics Review of CBPR?

CBPR raises research ethics considerations that go beyond those normally assessed by IRBs

- Shift from regarding individual community members as research *subjects* to engaging community members and the organizations that represent or serve them as research *partners*
- Iterative, participatory nature of study design & implementation
- Institution-based IRBs are designed to protect the rights and welfare of *individual* study participants, not the *communities* involved in research



CBPR Ethics Review

Institution-Based

- IRB expands #/role of community members
 - HIV REB at University of Toronto, co-sponsored with Ontario HIV Treatment Network
- IRB revises process for reviewing CBR
 - University of Washington
- IRB forms specific committee to review CBR
 - Michigan State University
- IRB serves as IRB for community partner
 - Silent Spring Institute and Brown University IRB



CBPR Ethics Review

Institution-Based

- IRB serves as IRB for CBOs
 - HIV REB at University of Toronto, co-sponsored with Ontario HIV Treatment Network
- IRB coordinates with community-based IRB
 - University of New Mexico & Navajo IRB
- IRB coordinates with community review process
 - Morehouse Medical School and its Prevention Research Center Community Committee
- Funder adopts additional ethics protections
 - Institute for Aboriginal Peoples' Health, Canadian Institutes of Health Research (CIHR)

CIHR Guidelines for Health Research in Aboriginal People

Community jurisdiction and approval

Research partnership methodology

Collective and individual consent

Confidentiality (collective and individual) and privacy

Respect for individual autonomy and responsibility

Inclusion of Indigenous knowledge in research

Protection of cultural knowledge

Benefit sharing

Empowerment and capacity development

Right to control collection, use, storage and potential use of data

Biological samples considered licensed to the researcher

Interpretation of results

Dissemination of results



CBPR Ethics Review

Community-Based

- Community-based IRB
 - Tribal nation: Navajo
 - CBO: Special Services for Groups, Los Angeles
 - Community health center: Waianae Coast, Hawaii
- Based in community-university partnership
 - Detroit Urban Research Center Community Board
 - University of Pittsburgh Community Research Advisory Board
- Based in community organization
 - Yakima Valley Farmworkers Clinic, WA
 - Access Alliance, Toronto



CBPR & Research Ethics Program

- 2007 Call Series Proceedings, “Ensuring Community-Level Research Protections”*
- CBPR & Ethics Listserv
- JERHRE Theme Issue on CBPR – Oct 2008
- IRB-REB Curriculum on Community-Engaged Research*
- **National Study, “Understanding Community-Based Processes for Research Ethics Review”**

**co-sponsored with Tuskegee Bioethics Center*



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
- *Ethics review:* University of Washington & UNE IRBs
- *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, Univ of WA
- **Sarah Flicker**, York University
- **Bill Freeman**, Northwest Indian College
- **Kelly Edwards**, Dept. of Medical Ethics, Univ of WA
- **Helen McGough**, Retired IRB Administrator, Univ 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 Maine
- **Stephen Sodeke**, Tuskegee Bioethics Center
- **Eric Wat**, Special Services for Groups in Los Angeles IRB

Methods

- **Online survey**
 - Reasons for developing the review process
 - Types of research reviewed
 - Review process functioning
 - Review process challenges and benefits
 - Relationship with institution-based IRBs
 - Interest in participating in collaborative research network

Study Participants

- **Database construction**
 - Bibliographic and funding databases
 - Online program conference agendas
 - Relevant list serves
- **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

Study Participants

- **Affiliation**

– Community-Institutional Partnerships	34 (31%)
– Community-based Organizations	24 (22%)
– Non-profit Organizations	13 (12%)
– Community Health Centers	13 (12%)
– Tribal Organizations	8 (7%)

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%)

Types of Research Reviewed (n=109)

Substantive focus	N (%)
Health Disparities	69(63%)
Diabetes	47(42%)
Cancer	45(41%)
Obesity	42(39%)
HIV; Mental Health	35(32%)

Type of Research Reviewed

(n=109)

Federal funding sources supporting submitted research	N (%)
National Institutes of Health	58(62%)
Centers for Disease Control and Prevention	41(44%)
Health Resources and Services Administration	28(30%)
Indian Health Service	12(13%)
Environmental Protection Agency	8(9%)

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%)

Concerns identified through the review process

- Risks & benefits
- Feasibility
- Engagement
- Relevance

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*

Challenges operating a review process

- Time
- Recruitment & support of engaged reviewers
- Coordination with external entities
 - *Conflict with other IRBs that do not address group harm*
 - *Some [researchers] are stuck in the old ways of doing research where they pay a few people and claim that they have community involvement*
- Infrastructure to support the review process

Involvement of an institution-based IRB (n=109)

Percentage of proposals reviewed by both the community group/partnership and an institution-based IRB	N (%)
100%	53 (49%)
75-99%	13 (12%)
50-74%	6 (6%)
25-49%	5 (5%)
1-24%	23 (21%)
0%	9 (8%)

Communication patterns when an institution-based IRB reviews the same proposal (n=92)

	N (%)
Our communication with the institution-based IRB varies from proposal to proposal	43 (47%)
We do not usually communicate with the institution-based IRB	31 (34%)
We usually communicate with the institution-based IRB if we have questions or concerns <i>during the review</i> of the proposal	20 (22%)
We usually communicate with the institution-based IRB <i>after</i> we have completed the review, and our requirements conflict with their requirements	10 (11%)

Reasons why a proposal is not reviewed by an institution-based IRB (n=87)

	N (%)
The group/partnership has its own registered IRB with OHRP	13 (15%)
The group/partnership's review process conducts a thorough review and thus an institution-based IRB is not required	9 (10%)
The group/partnership lacks access to an institution-based IRB	5 (6%)
The cost of an institution-based IRB review	4 (5%)
Lack of satisfaction with the institution-based IRB review	2 (2%)
Other	29 (33%)

Quality of relationship between the community review process and the institution-based IRB (n=94)

- Over half described relationship as positive
 - 24% as “extremely positive”
 - 32% as “somewhat positive”
- 40% reported relationship to be “neither positive nor negative”
- 3% reported relationship to be “somewhat negative”

Significant challenges when working with an institution-based IRB

	N (%)
Time delays	22 (42%)
Institution-based IRB's lack of understanding of CBPR	20 (38%)
Communication with the institution-based IRB	11 (21%)
No challenges	10 (19%)
Resolution of issues with multiple institution-based IRBs	7 (13%)
No contact with the institution-based IRB	4 (8%)

Study Limitations

- Study sample
- Response rate
- Questions asked

Study Implications...

- Role of communities in research
- Consideration of community risks & benefits
- Definition of ethical research
- Relationship between community-based & institution-based research ethics review
- Thorough ethical analysis in a timely manner
- Capacity issues



Planned Next Steps

- Conduct in-depth case studies
- Support CCPH learning community
- Develop practical resources
 - Online repository
 - Guidebook
 - Technical assistance

Selected Citations

1. Shore, N. (2006). Re-conceptualizing the Belmont Report: A community-based participatory research perspective. *Journal of Community Practice, 14*(4), 5-26.
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. Grignon J, Wong K & Seifer S. (2008). Ensuring Community-Level Research Protections. Proceedings of the 2007 Educational Conference Call Series on Institutional Review Boards and Ethical Issues in Research. Seattle, WA: Community-Campus Partnerships for Health.
4. Quinn SC. (2004). Ethics in public health research: Protecting human subjects: The role of community advisory boards. *American Journal of Public Health, 94*(6), 918-922.
5. Shore N, Brazuaskas R, Drew E, Wong KA, Moy L, Baden AC, Cyr K, Ulevicus J & Seifer SD. (2010). Understanding community-based processes for research ethics review: A national study. *American Journal of Public Health*. Published online ahead of print December 16, 2010: e1–e6. doi:10.2105/AJPH.2010.194340
6. Shore N, Drew E, Brazauskas R & Seifer SD (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 (in press).



Tap into Resources!

www.ccph.info

Upcoming Events

- CCPH 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

Community-Campus Partnerships for Health

*We invite you to join a growing network of communities & campuses
that are collaborating to promote health*

Contact us by phone 206-666-3406 or
email at info@ccph.info or
visit us online at www.ccph.info



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