PARTNERS HUMAN RESEARCH COMMITTEE Guidance Document Community-Based Participatory Research (CBPR)

Community-based participatory research (CBPR) is a collaborative process of research between trained researchers and community representatives to solve problems relevant to human health in communities. Members of the community are involved in all aspects of the research including design, analysis, and dissemination of results.

There are a number of resources available for investigators who plan to conduct CBPR that discuss basic principles of CBPR, ethical issues, and training for academic and community partners. In addition, Harvard Catalyst provides consultation services for Harvard-affiliated researchers who are planning CBPR. Links are provided at the end of this document.

IRB REVIEW OF CBPR PROJECTS:

The Partners Human Research Committee acknowledges that a community-based participatory approach to research is an evolutionary process for investigators and community partners. Review of protocols will focus on protection of the subjects and communities. As appropriate, investigators should consider the following principles and aim to integrate them into their protocol development:

Principles

The research should aim to facilitate collaborative, equitable partnerships with the community at all stages of the research. This includes, planning and implementing the research and disseminating research results.

If possible, community members should be involved with the identifying the issues of concern and need for the research. In addition they need to be involved in designing, planning and implementing the research. This permits building on the community strength and resources and promotes co-learning and capacity building among all partners. This also helps emphasize the local relevance of the issues to be studied

The risks and benefits to individuals and the community must be considered. The community needs to be recognized as a unit of identity. Minimize risks and maximize benefits by:

- Using community collaborators to identify culturally appropriate perspectives
- Capacity building within the community to empower

Protocol Tips

Study Description: Include the community's role in planning, conducting and/or disseminating results of the research. When appropriate, include a plan to inform community members about the results of the research study and utilize community members to help disseminate results.

Consider the following in disseminating and/or publishing results of research:

- Are there group harms/risks with unflattering or "bad" findings about the group?
- Even if those outside the community can't identify someone, can they identify each other?
- Are there agreements up front to avoid problems later down the line?

Describe any risks and benefits to the community as a whole. Consider:

- How the research might further stigmatize vulnerable populations
- Emotionally charged topics and possible fractures in the community

Describe what has been put in place to minimize the risks to the community.

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Consider how cultural or community attitudes
may affect your research. In writing your
protocol consider such things as:
 Are the research methods sensitive to
and appropriate for the community?
(language, literacy, cultural or
community attitudes).
 Are recruitment methods appropriate
to the community?
Is the consent process appropriate?
 Have appropriate permissions been
obtained?
 Is it appropriate for community
members to have access to
identifiable data?
For international research refer to Guidance.
If applicable to IRB submission, describe
capacity building opportunities or tools.
 If members in the community will be
involved in recruitment and/or data
collection has education/training been
provided, if appropriate?
How are barriers to community
participation in planning and
implementing the research being
addressed?

LINKS TO RESOURCES:

<u>CBPR Consulting Program</u> - Through the CBPR Consulting Program, Harvard-affiliated investigators and their community partners can receive advice and training on incorporating a community-based participatory research approach into their work.

Harvard Catalyst Resources on CBPR

As part of the Community Engagement Core of the Harvard Catalyst, the CBPR program is focused on promoting community participation in research and supporting the use of CBPR by Harvard investigators. Find links to education, training, and articles here..

<u>Community-Campus Partnerships for Health</u> (CCPH) is a nonprofit organization that promotes health (broadly defined) through partnerships between communities and higher educational institutions. Links to information on planning and conducting research, research ethics and IRBs, and research grants may be found here.

Ethics and Research in the Community

A training tutorial for lay individuals who do research in the community, funded by the Office of Research Integrity. Training topics include: "The Research Protocol", "Recruiting Participants", "Confidentiality", "Professionalism", and "Applications

Developing and Sustaining CBPR Partnerships: A Skill-Building Curriculum

This curriculum is intended as a tool for community-institutional partnerships that are using or planning to use a CBPR approach to improving health. It can be used by partnerships that are just forming as well as mature partnerships.

CPBR at PARTNERS HEALTHCARE SYSTEM (PHS)

Institute for Community Health

http://www.icommunityhealth.org/index.html

<u>Disparities Solution Center at MGH</u>
http://www2.massgeneral.org/disparitiessolutions/index.html

BWH The Center for Community Health and Health Equity http://www.brighamandwomens.org/communityprograms/

BWH: 2010 Community Benefit Report to the Attorney
Generalhttp://www.brighamandwomens.org/communityprograms/09BWH.pdf

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