

## Handout #1 – Definitions, Rationale, and Key Principles in CBPR

### Definition

The Kellogg Foundation is one of the leading private funding agencies supporting CBPR research and the training of community research scholars. They define CBPR as:

“A collaborative *approach* to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings”.

--W.K. Kellogg Foundation (2001)

Key words here are “collaborative,” “equitably,” and “partners.” The intent is to transform research from a relationship where researchers act upon a community to answer a research question but instead, researchers work side by side with community members to define the questions, methods and disseminate the information. Community members become part of the research team and researchers become engaged in the activities of the community.

### Rationale

The rationale for CBPR builds on a history of both domestic and international activism that dates back to the 1940s. Below are reasons why more researchers today are increasingly turning to CBPR approaches to research:

- **There is a growing recognition that “traditional” research approaches have failed to solve complex health disparities.** Many research designs fail to incorporate multi-level explanations of health and the researchers themselves do not understand many of the social and economic complexities motivating individuals’ and families’ behaviors.
- **Community members themselves, weary of being ‘guinea pigs’ are increasingly demanding that research address their locally identified needs.** Traditional researchers often complain about challenges in trying to recruit “research subjects.” These challenges are often a result of community members feeling that researchers have used them and taken findings away for the researchers benefit (e.g., scholarly papers) but the community is left with no direct benefit.
- **Significant community involvement can lead to scientifically sound research.** Researchers using participatory methods have found community input invaluable in the design and adaptation of research instruments to make the tools user friendly, applicable and culturally appropriate.
- **Research findings can be applied directly to develop interventions specific for communities.** The specific outcome of CBPR research is not simply to find answers to complex social questions but to have those results provide information that can be used by the research community to define its own solutions.

- **This approach to research has the potential to build greater trust and respect between researchers and communities.** Trust and respect are two common reasons why individuals do not participate in research. If the research design and methods actively engages the voices of community members in an equitable manner, trust is likely to build.

### **Key Principles**

Developing community-based partnerships that are successful in developing relationships and research initiatives that are locally relevant take time and patience. A number of authors have advanced principles for community-based participatory research. Drawing on over a decade of experience, Israel (1998) and her colleagues have identified eight key principles of community-based participatory research that support successful research partnerships and are widely cited. These include:

1. Recognizes community as a unit of identity
2. Builds on strengths and resources within the community
3. Facilitates collaborative partnerships in all phases of the research
4. Integrates knowledge and action for mutual benefit of all partners
5. Promotes a co-learning and empowering process that attends to social inequalities
6. Involves a cyclical and iterative process
7. Addresses health from both positive and ecological perspectives
8. Disseminates findings and knowledge gained to all partners

While principles are a useful guide, Israel and her colleagues caution that they should not be imposed upon a project, and that they should be allowed to continually evolve to reflect changes in the research context, purpose and participants. The process of developing principles and making decisions about the partnership's characteristics is essential to building the infrastructure of the partnership.

## **Handout #2 – Public Health Code of Ethics and Ethical Issues in CBPR**

If one examines the ethical principles of public health research and practice set out by the American Public Health Association and the Associated Schools of Public Health (see *below*), one can see a heavy emphasis on involving the community in the design of public health interventions, policy and research. This reflects in part a communitarian tradition in public health that looks beyond the individual: “This [communitarian] theory is based on a recognition that individual liberty and indeed human existence relies heavily upon the interdependent and overlapping communities to which all of us belong (families; neighbourhoods; workplace, religious and other social groups).”

(<http://www.shef.ac.uk/~scharr/public/research/ethics/>)

### **Principles of the Ethical Practice of Public Health**

- 1) Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.
- 2) Public health should achieve community health in a way that respects the rights of individuals in the community.
- 3) Public health policies, programs, and priorities should be developed and evaluated through processes that ensure an opportunity for input from community members.
- 4) Public health should advocate and work for the empowerment of disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.
- 5) Public health should seek the information needed to implement effective policies and programs that protect and promote health.
- 6) Public health institutions should provide communities with the information they have that is needed for decisions on policies or programs and should obtain the community's consent for their implementation.
- 7) Public health institutions should act in a timely manner on the information they have within the resources and the mandate given to them by the public.
- 8) Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.
- 9) Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.
- 10) Public health institutions should protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions must be justified based on the high likelihood of significant harm to the individual or others.
- 11) Public health institutions should ensure the professional competence of their employees.
- 12) Public health institutions and their employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness.

Source: <http://www.apha.org/codeofethics/>

### **Unique issues in CBPR**

Protecting the privacy and confidentiality of research participants is sometimes a challenge in CBPR when community members become ‘participant researchers’ who are active in the research design, data collection and analysis. In qualitative data analysis, it is common for researchers to go back to research participants to confirm the findings and interpretations of results. This may preclude having completely anonymous research participants or may require more protections around confidentiality of participants.

In CBPR, because everyone’s participation is highly valued, role definitions between researchers and community members can sometimes become blurred.

- When should a researcher take responsibility and ownership of critical measurement or methodological questions?
- When might asking community members for input on design issues prove burdensome and/or threatening if it is not an area they know?
- How does “equity” in the CBPR process get translated into practice so that divisions of labor and input are not exploitative to any one partner?

Disseminating research results on CBPR projects also involves participation from both community members and researchers.

- How do research results get re-presented and whose voice(s) is/are heard or represented?
- Are the findings presented in an accessible and meaningful way for community members?
- Are the findings presented in scientifically valid and rigorous means for academic audiences?
- What if the research findings in economically disadvantaged communities reinforce negative social stereotypes?
- Would it do more harm to the community to report such findings?

These are just some examples of ethical issues that might arise in the design and implementation of a CBPR project as well as questions that might come forward from an IRB reviewing such a proposal.

### Handout #3 - Comparison of CBPR and Traditional Research

