

## Unit 1: CBPR – Getting Grounded

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This unit covers the basics of CBPR and is foundational to the remaining units in the curriculum.

### **Learning Objectives**

- Explain the theoretical basis, definition, rationale and key principles of CBPR
- Describe how CBPR differs from traditional research approaches
- Identify ethical considerations for researchers and community partners

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## Unit 1 Section 1.1: Definitions, Rationale and Key Principles in CBPR

### Definitions

There are multiple definitions for community-based participatory research (CBPR). We have chosen to highlight the definition used by the Community Health Scholars Program, a WK Kellogg Foundation-funded post-doctoral fellowship program in CBPR. The program defines CBPR as:

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

~ Community Health Scholars Program

Key words here are “collaborative,” “equitably,” “partners,” “combining knowledge with action” and “achieving social change.” The intent in CBPR is to transform research from a relationship where researchers *act upon* a community to answer a research question to one where researchers *work side by side* with community members to define the questions and methods, implement the research, disseminate the findings and apply them. Community members become part of the research team and researchers become engaged in the activities of the community. For a comparison of the how the CBPR process compares to that of traditional research, [see Figure 1.1.1](#)

### Rationale

CBPR has its roots in social and political movements of the 1940s, which saw a revitalization in the 1960s and 1970s. In the 1940s Kurt Lewin began talking about *action research* as a means to overcoming social inequalities; he also rejected the notion that in order for researchers to be “objective” they needed to remove themselves from the community of interest. Later writings by educator Paulo Freire in the 1970s brought to the fore issues of having communities identify their own problems and solutions.

The rationale for CBPR builds on this history. Below are reasons why more communities and 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 community to develop 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 engage community members in an equitable manner, trust is likely to build.

### **Key Principles**

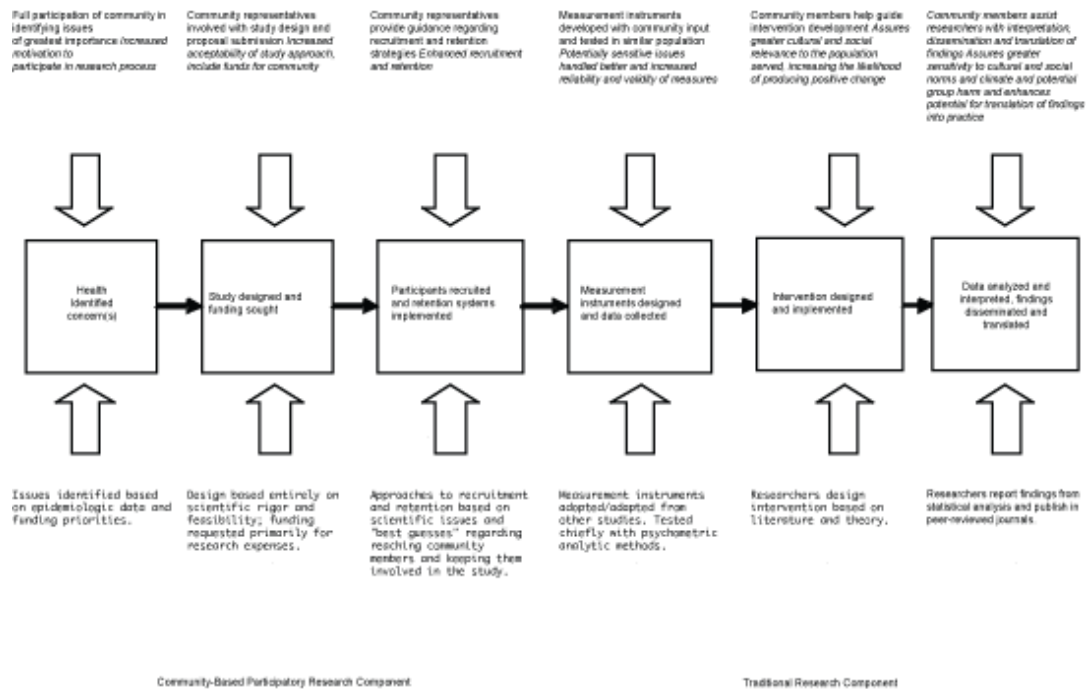
Developing community-based partnerships that are successful in creating relationships and research initiatives that are locally relevant take time and patience. A number of authors have advanced principles for CBPR. Drawing on over a decade of experience, Barbara Israel and her colleagues have identified eight key principles of CBPR that support successful research partnerships and are widely cited.

These include:

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

While principles are a useful guide, they should not be imposed upon a project or partnership, 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.

### **Figure 1.1.1: Comparison of CBPR and Traditional Research**



[Click here to enlarge Fig. 1.1.1](#)

## Exercise 1.1.2: Discussing the Definitions, Principles and Rationale of CBPR

You are about to have your first full meeting of your CBPR partnership.

Consider the following questions and then develop your agenda for the first meeting:

- Do you believe it is necessary to discuss these definitions and principles of CBPR and their rationale at the first meeting? Why or why not?
- If you decide to include discussions of some or all of them, who should bring these up and how?
- What power dynamics would you want to consider in a discussion of this nature?

**Assignment:** Write the agenda for the first partnership meeting. Be sure to include: the meeting purpose/goal; the meeting chair(s); the meeting timeframe/location. Describe each item for discussion on the agenda clearly, along with who is expected to facilitate it. Be prepared to present and discuss your agenda and its rationale.

## Unit 1 Section 1.2: Benefits of CBPR

Successful CBPR partnerships demonstrate tangible benefits to all of the partners involved. All partners enhance their capacity and learn from their involvement.

### Examples of tangible benefits for all partners include the following:

- Knowledge and skills of partners to work collaboratively and in more participatory ways
- Ability to gain a more complex understanding of each other's strengths and limitations
- Relationships and support for each other's work as well as the establishment of new collaborative efforts through increased networking and collaboration among the partners
- Ability of community partners and researchers to learn from and influence one another
- Ability and willingness to serve as primary resources for one another
- Learn new ways of thinking about their own work
- Reconsidering the appropriateness of their measures and techniques in light of new perspectives
- Opportunities for enhanced professional development to enable all partners to gain or enhance needed competencies

### Examples of tangible benefits for institutional partners include the following:

- Learn more about local resources and services
- Gain understanding of community history, culture and dynamics and how interventions in other communities may or may not apply to local circumstances
- See evidence of how community experiences can improve the research process

### Examples of tangible benefits for community partners include the following:

- Gain understanding of institutional history, culture and dynamics and how certain decisions about research design could impact the credibility of the results
- See evidence of how their experiences can improve the research process
- Obtain data that validates their concerns to the "outside world" and provides "proof" that policymakers, the media, and other high-level decision makers require before they believe that the issue deserves their attention
- See resulting benefits in the community

**Table 1.2.1 below displays some of the potential benefits and challenges of CBPR to participating communities and researchers.**

**Table 1.2.1 : Critical Elements in CBPR**

Source: Viswanathan M. et. al.

CBPR Implementation and Potential Impact				
Research Element	CBPR Application	Community Benefits	Research Benefits	Research Challenges
Assembling a research team of collaborators with the potential for forming a research partnership	Identifying collaborators who are decision makers that can move the research project forward	Resources can be used more efficiently	Increases the probability of completing the research project as intended	Time to identify the right collaborators and convincing them that they play an important role in the research project
A structure for collaboration to guide decision-	Consensus on ethics and operating	The beginning of building trust and the likelihood that	An opportunity to understand each collaborator's	An ongoing process throughout the

making	principles for the research partnership to follow, including protection of study participants	procedures governing protection of study participants will be understood and acceptable	agenda, which may enhance recruitment and retention of study participants	life of research partnerships that requires skills in group facilitation, building consensus, and conflict accommodation
Defining the research question	Full participation of community in identifying issues of greatest importance; focus on community strengths as well as problems	Problems addressed are highly relevant to the study participants and other community members	Increased investment and commitment to the research process by participants	Time consuming; community may identify issues that differ from those identified by standard assessment procedures or for which funding is available
Grant proposal and funding	Community leaders/members involved as a part of the proposal writing process	Proposal is more likely to address issues of concern in a manner acceptable to comm. unity residents	Funding likelihood increases if community participation results in tangible indicators of support for recruitment and retention efforts, such as writing letters of support, serving on steering committee or as fiscal agents or co-investigators	Seeking input from the community may slow the process and complicate the proposal development effort when time constraints are often present
<b>Research Element</b>	<b>CBPR Application</b>	<b>Community Benefits</b>	<b>Research Benefits</b>	<b>Research Challenges</b>
Research design	Researchers communicate the need for specific study design approaches and work with community to design more acceptable approaches, such as a delayed intervention for the control group	Participants feel as if they are contributing to the advancement of knowledge vs. as if they are passive research "subjects," and that a genuine benefit will be gained by their community	Community is less resentful of research process and more likely to participate	Design may be more expensive and/or take longer to implement; possible threats to scientific rigor
Participant recruitment and retention	Community representatives guide researchers to the most effective way to reach the intended study participants and keep them involved in the study	Those who may benefit most from the research are identified and recruited in dignified manner rather than made to feel like research subjects	Facilitated participant recruitment and retention, which are among the major challenges in health research	Recruitment and retention approaches may be more complex, expensive, or time consuming
Formative data collection	Community members provide input to	Interventions and research approach are	Service-based and community-based	Findings may indicate needed changes to

	intervention design, barriers to recruitment and retention, etc. via focus groups, structured interviews, narratives, or other qualitative method	likely to be more acceptable to participants and thus of greater benefit to them and the broader population	interventions are likely to be more effective than if they are designed without prior formative data collection	proposed study design, intervention, and timeline, which may delay progress
Measures, instrument design and data collection	Community representatives involved in extensive cognitive response and pilot testing of measurement instruments before beginning formal research	Measurement instruments less likely to be offensive or confusing to participants	Quality of data is likely to be superior in terms of reliability and validity	Time consuming; possible threats to scientific rigor
<b>Research Element</b>	<b>CBPR Application</b>	<b>Community Benefits</b>	<b>Research Benefits</b>	<b>Research Challenges</b>
Intervention design and implementation	Community representatives involved with selecting the most appropriate intervention approach, given cultural and social factors and strengths of the community	Participants feel the intervention is designed for their needs and offers benefits while avoiding insult; provides resources for communities involved	Intervention design is more likely to be appropriate for the study population, thus increasing the likelihood of a positive study	Time consuming; hiring local staff; may be less efficient than using study staff hired for the project
Data analysis and interpretation	Community members involved regarding their interpretation of the findings within the local social and cultural context	Community members who hear the results of the study are more likely to feel that the conclusions are accurate and sensitive	Researchers are less likely to be criticized for limited insight or cultural insensitivity	Interpretations of data by non-scientists may differ from those of scientists, calling for thoughtful negotiation
Manuscript preparation and research translation	Community members are included as coauthors of the manuscripts, presentations, newspaper articles, etc., following previously agreed-upon guidelines	Pride in accomplishment, experience with scientific writing, and potential for career advancement; findings are more likely to reach the larger community and increase potential for implementing or sustaining recommendations	The manuscript is more likely to reflect an accurate picture of the community environment of the study	Time consuming; requires extra mutual learning and negotiation

### **Exercise 1.2.2: Understanding Critical Elements in CBPR**

Find an article on CBPR describing its research design and outcomes and ask all participants to read it in advance (see [Appendix C](#) and [Appendix D](#) for suggestions). Depending on the size of the group, do this exercise as a full group or divide into groups of 4-6. Give each group an article with a different research design (e.g., quantitative, qualitative, mixed methods). Ask each group to read the paper and answer the following questions:

- Describe the overall research design (rationale, objectives, methods, time frame, population, partners).
- Identify the key areas in the research design that distinguish this as CBPR.
- Who are the partners?
- 
- Who is the community?
- 
- What is the issue being addressed? What are the anticipated health outcomes to be achieved?
- 
- How will progress towards objectives be measured?
- How will the results be evaluated?
- How will the results be disseminated?
- Identify parts of the design where you have concerns about rigor, objectivity or bias. Explain.
- Identify parts of the design where you have concerns about the partnership and/or involvement of the community. Explain.
- Identify areas of the design where you have ethical concerns. Explain.
- What would you have done differently?

Ask each group to report back to the whole group on common issues of concern as differences in the CBPR designs presented. Ask the whole group problem solve on how to address the various concerns raised in future and current work being done by their partnership(s).

## Unit 1 Section 1.3: Ethics and CBPR

### What are the ethical issues that may affect community participation in research?

If one examines the ethical principles of public health set out by the American Public Health Association and the Association of Schools of Public Health in Box 1.1, 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.” (*Ausubel*)

Historically, however, many research designs have not adequately or appropriately involved community participants, resulting in a negative perception of research. Common problems experienced by communities in research include:

- Irrelevance to the community
- Poor methodology that in turn is a waste of resources
- Research data and findings are not given back
- Communities feel “over-researched”
- Communities feel coerced to participate in research
- Communities feel researched upon rather than partners in the process
- Communities are lied to
- Insensitivity to community concerns or issues
- Benefits to community are minimal or nonexistent

CBPR attempts to address these issues and concerns both in the design of the research and its conduct from being respectful of participants, listening, and having cultural competence. As with any research study, it cannot coerce participation: “American political culture does not recognize an obligation to participate in research; rather, we consider it to be a socially desirable activity that people may elect to participate in or not, as they choose” (*Pritchard*).

Given that CBPR by definition requires a significant level of community member participation with the objectives of community improvement and social change, the ethical practice of CBPR requires researchers to be vigilant about the way the partnership is developed, implemented, and sustained. For example, an ethical CBPR practitioner would not promise communities more than s/he believes the partnership can deliver, nor would s/he exploit community members’ time and expertise for personal gain.

#### **Table 1.3.1: Principles of the Ethical Practice of Public Health**

- Public health should address principally the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.
- Public health should achieve community health in a way that respects the rights of individuals in the community.
- Public health policies, programs, and priorities should be developed and evaluated through processes that

ensure an opportunity for input from community members.

- 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.
- Public health should seek the information needed to implement effective policies and programs that protect and promote health.
- 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.
- 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.
- Public health programs and policies should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.
- Public health programs and policies should be implemented in a manner that most enhances the physical and social environment.
- 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.
- Public health institutions should ensure the professional competence of their employees.
- 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: Principles of the Ethical Practice of Public Health, Version 2.2*

## **What are examples of ethical issues that arise in CBPR?**

Below, we briefly review ethical issues that may arise in the conduct of CBPR. 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 must be considered and might come forward from an IRB reviewing the research proposal.

### **Community participation**

In CBPR, questions around “who is the community,” “who represents the community,” and “who speaks for the community” are all critically important.

- Is it legitimate or ethical for community members to come from only a few neighborhoods or social identity groups, thus benefiting some communities more than others?
- What if certain neighborhoods or communities are more outspoken, have greater community organizing skills, or are more comfortable negotiating with academic researchers than others?
- Do academic researchers have a responsibility to seek participation from all communities, or just work with the groups who are the most outspoken, or easiest, to work with?

### **Roles**

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?

### **Dissemination of research results**

Disseminating CBPR research results 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?  
Exercise 1.3.2 is designed to help partners to consider the various types of ethical issues which may arise during a CBPR project.

### **Exercise 1.3.2: Considering Ethical Issues that can Arise in CBPR**

A community-academic partnership has formed to conduct formative research on the relationship between the crack cocaine epidemic and the spread of sexually transmitted infections, particularly HIV, in a large, urban African-American neighborhood. Partnership members include university researchers, local health department representatives, substance abuse treatment providers, a neighborhood coalition, and recovering addicts from local neighborhoods. Through focus groups with African-American women crack users currently in treatment, the partnership learned that women would often have unprotected sex with multiple partners in a single day in order to buy crack to feed their drug addiction. Women told stories about 13 year-olds in hallways performing oral sex for \$3. Other research findings highlighted some of the changes in the urban environment that placed greater stressors on families. For example, a number of women had come from formerly family-owned housing that had burned out in poorer neighborhoods that were under-supported by the city fire department. Given the lack of adequate cheap housing, families split up, sometimes ending up in cheap, temporary hotels. There, through depression, lack of job opportunities, and an environment of drugs and violence, many women (and girls) turned to crack cocaine use and prostitution.

#### **Discussion Questions:**

- In representing these findings, what ethical considerations might you have in terms of harms to the

community?

- What are potential benefits to the community in having these findings disseminated?
- Who should decide when and how to present the data?
- Who should represent these findings and how should they be represented and disseminated?
- *Data for this exercise comes from [The Secret Epidemic](#) by J Levenson; the partnership itself is fictional.*

### **Exercise 1.3.3: Identifying Ethical Issues in the CBPR**

#### **Process**

**Instructions:** Form groups of 3-4 people. Assign each group one of the six boxed steps in the research process, portrayed in [Table 1.2.1](#), and ask them to complete the three items below in 30 minutes. Instruct each group to identify a recorder to take notes and a reporter to present back to the larger group.

1. Based on the step in the research process assigned, ask each person in the group to give an example of how their partnership has dealt with this step in a particular research project and where they fall in the continuum between traditional research and CBPR. In giving examples, consider what the challenges were, what the successes were (what made it work?) and unexpected discoveries or “ah-ha” moments. The recorder should try to take note of commonalities/differences between stories/experiences.

2. Brainstorm as a group the specific ethical issues that might arise in a CBPR project at this particular step. Draw on participant examples to develop a list.

3. Share examples of ethical issues that arose in CBPR projects you have been involved with. What lessons might we learn from your experience?

Reconvene the small groups as a large group to report on their discussion. Explore themes and challenges that cut across the groups and those that are unique to particular steps in the research process.

### **CBPR and Institutional Review Boards**

Like any other research endeavor involving human subjects, CBPR protocols and designs require the review of institutional review boards (IRBs) to assure the protection of participants in the study. The role of IRBs is to assure that studies maximize benefit and minimize risk to all participants. In most institutional-community partnerships, the participating university, community health agency, public health department or hospital partner have one or more IRBs that review the research design.

#### **What are the primary ethical principles that guide the ethical review process?**

The ethical guidelines built in to most IRBs rely largely on three core ethical principles: respect for persons, beneficence and justice. These derive from different philosophical traditions and at times can come into conflict with one another in determining which principle should take priority over another. The principle of respect for persons underlies the obligation to obtain informed consent; the principle of beneficence

demands the maximizing of benefit and minimizing of risks; and the principle of justice requires the equitable distribution of the burdens and the benefits of research. A more comprehensive list of ethical principles that guide research includes:

- Respect for human dignity
  - Respect for free and informed consent
  - Respect for vulnerable persons
  - Respect for privacy and confidentiality
  - Respect for justice and inclusiveness
  - Balancing harms and benefits
  - Minimizing harms
  - Maximizing benefits
  - Equitable distribution of the burdens and benefits of research
- CBPR is deliberately intended to be a flexible and adaptive research design. As a result, this may require additional bureaucratic steps with the IRB, informing them of design changes and assuring them that they continue to follow all ethical principles.

In CBPR, research involving institutions such as schools, churches or workplaces, the issue of “voluntariness” may sometimes arise. In a situation where institutional leaders (e.g., principals, teachers, pastors, managers) and peer leaders have endorsed a CBPR study, it is important to assure that not all members of those organizations feel compelled to participate in the study and that non-participation will not result in any reprisals.

This issue is closely related to “informed consent.” In all studies, participants are required to either indicate orally with a witness or in written form by signing an informed consent form that they fully understand the study and their role, they are competent to participate and their participation is voluntary. Although it is sometimes overlooked, Pritchard and other researchers remind us that informed consent should be more than a form – it should be a process.

### **Example 1.3.4: Informed Consent as a Process**

In describing the ethical steps in conducting photovoice as a form of CBPR, Wang and Redwood-Jones highlight the importance of informed consent throughout the process of the study. In photovoice, community members are given cameras and asked to record through photographs pertinent issues in their lives around specific public health themes. Community photographers sign their own informed consent forms (or assent forms for youth) to indicate their agreement to participate and then begin with an introduction to the ethical principles of photographing others and the power of the camera. Once they begin taking pictures, the photographers are required to obtain a second signed consent form, “Acknowledgements and Release” from potential photo subjects *before* they take the picture. Finally, if the research team and photographers decide that they would like to publicly display a photograph of an individual in a public forum or publication, they go back to the individual to

have them sign a third consent form. This assures that the individual in the photograph is fully informed throughout the process and can control for any potentially embarrassing or incriminating photographs of themselves.

*Citation: Wang and Redwood-Jones*

It is important for community partners to understand the IRB process involved in the research project. At the end of the day, community partners want to be sure that the research is helping the community by solving community problems. The IRB is a protective mechanism that community partners can use if they understand it and are part of the process of designing the research. Once community partners are clear that the human subject issues have been addressed, they can promote the research project with greater confidence. In the words of one community partner involved in a CBPR partnership, *"If I understand the IRB, I have greater confidence in my outreach to my community and advocacy for the project. Because of the trusting relationship developed through this process, I feel a greater degree of confidence in the intended outcomes that will result from this research. Because we have more of an understanding and know the questions to ask, we can go out and explain it to the community and know that it's good research because we have been engaged in ensuring that we will get the intended outcome."*

### **Designing a study protocol to submit for IRB review**

Research protocols submitted to IRBs for review generally cover these topics:

- (1) Background, purpose and objectives
- (2) Research methods
- (3) Population or research participants
- (4) Recruitment of participants
- (5) Risks and benefits
- (6) Privacy and confidentiality
- (7) Compensation
- (8) Conflicts of interest
- (9) Informed consent process

Below, we walk through the purpose of each of the topics and raise questions for consideration regarding ethics and community participation.

(1) Background, purpose and objectives: This section describes the background and setting to the project, its rationale, purpose, objectives and hypothesis for research.

#### ***Questions to consider:***

- Is this research really justified?
- Who benefits? How?
- How was the community involved or consulted in defining the need?

- Who came up with the objectives and how?
- Are there concrete action outcomes?

*(2) Research methods: This section describes how the research will be done. It describes the who, what, where, when and how of the research. It indicates what procedures will be used to collect data (e.g., surveys, interviews, focus groups), the frequency of these procedures and the number of people involved. It indicates the period of time the research will be carried out and how long each phase will last.*

**Questions to consider:**

- How will the community be involved? At what levels?
- What training or capacity building opportunities will you build in?
- Will the methods used be sensitive and appropriate to various communities (consider literacy issues, language barriers, cultural sensitivities, etc.)?
- How will you balance scientific rigor and accessibility?

*(3) Population targeted or research participants: This section describes who the participants are and why they were selected. It states the proposed "sample size" (e.g., how many people will be involved) and how that size was determined. It provides any relevant inclusion or exclusion criteria for who can be involved in the study and describes any special issues with the proposed study population, (e.g., incompetent patients or minors)*

**Questions to consider:**

- Are you really talking to the "right" people to get your questions answered appropriately (e.g., service providers, community members, leaders, etc.)?
- How will you protect vulnerable groups?
- Will the research process include or engage marginalized or disenfranchised individuals? How?
- Who speaks for the community?
- Is there a reason to exclude some people? Why?
- Are the potential research benefits and harms likely to be shared relatively equally among all participants?

*(4) Recruitment: This section describes how and by whom participants will be approached and recruited. It includes copies of any recruiting materials (e.g., letters, advertisements, flyers, telephone scripts). It states where participants will be recruited from (e.g., hospital, clinic, school). It provides a statement of the investigator's relationship, if any, to the participants (e.g., physician, teacher, community public health representative).*

**Questions to consider:**

- What is the power relationship between the investigator(s) and participants? Is there potential for coercion?
- Are the service providers and researchers different people?
- Is it clear to the population that they may still receive services even if they choose not to participate in the research?
- Who approaches people about the study and how?
- Are your recruitment strategies and materials culturally appropriate and adapted to the participants?
- How will you assure confidentiality?

*(5) Risks and benefits: This section describes the anticipated risks and benefits to research participants. It explains how these risks and benefits are balanced and what strategies are in place to minimize and*

manage any risks.

**Questions to consider:**

- *What are the risks for communities? For individuals?*
- *Have you been fully honest about risks? How will you minimize these?*
- *Are there built in mechanisms for how unflattering results will be dealt with? Are your recruitment strategies and materials culturally appropriate and adapted to the participants?*
- *Is it clear and transparent who will benefit from this research and how?*
- *How do you distribute the benefits most equitably?*

*(6) Privacy and confidentiality: This section provides a description of how privacy and confidentiality will be protected. It includes a description of data maintenance, storage, release of information, access to information, use of names or codes, destruction of data at the conclusion of the research and includes information on the use of audio or videotapes. 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.*

**Questions to consider:**

- *How do you maintain boundaries between multiple roles (e.g., researcher, counselor, peer)?*
- *What processes will you put in place to be inclusive about data analysis and yet maintain privacy of participants?*
- *Where will you store data? Who will have access to the data? How? Is it clear and transparent who will benefit from this research and how?*
- *What rules will you have for working with transcripts or surveys with identifying information?*

*(7) Compensation: This section describes any reimbursements, remuneration or other compensation that will be provided to the participants, and the terms of this compensation.*

**Questions to consider:**

- *Are people being reimbursed for their time and effort? If so, how can this be done without being “coercive”?*
- *Have you consider other types of compensation such as travel or parking costs and childcare?*
- *Who is managing the budget? Which partners are getting what compensations?*
- *Who is being paid? Who is volunteering? How are those decisions being made?*
- *Have you assured that participation in the research and service delivery are not being linked?*

*(8) Conflicts of interest: This section provides information relevant to actual or potential conflicts of interest (to allow the IRB to assess whether this information should be shared with participants as part of the informed consent process).*

**Questions to consider:**

- *What happens when your job depends on the results?*
- *What happens when you are the researcher and the*
  - *Friend*
  - *Peer*
  - *Service Provider*
  - *Doctor, nurse, social worker*

- Educator
- Funding agency?

*(9) Informed consent process: This section describes the procedures that will be followed to obtain informed consent from participants. It includes a copy of the information letter(s) and consent form(s). If written informed consent is not being obtained, it explains why. Where minors are to be included as participants, a copy of the assent script to be used is provided. If you are dealing with a population with special needs (e.g., illiterate) or with a different language base, how these differences will be addressed to assure that they are fully informed is explained.*

**Questions to consider:**

- *What does this mean for “vulnerable” populations (e.g., children, mentally ill, developmentally challenged)?*
- *What does it mean to inform?*
- *What does it mean to “consent”?*
- *How do you do this in a culturally sensitive manner?*
- *Whose permission do you need to talk to whom?*

## Unit 1 Section 1.4: Determining if CBPR is Right for You

CBPR has gained recognition as a viable approach to research. Increasingly, funding agencies are requesting that researchers engage communities as research partners in grant proposals. But CBPR is not for everyone or every community or every research question. When exploring the possibility of engaging in a CBPR partnership, it is advised that all parties consider asking themselves the questions below to guide a discussion about the feasibility of working together. It is important to address these potentially difficult conversations as a way to assess whether or not a CBPR partnership model is even appropriate.

**Before starting down the road to CBPR, ask yourself the following questions:**

### I. Is opportunism and self-interest driving the agenda?

Certainly, enlightened self-interest may underlie a person's or organization's desire to engage in a CBPR partnership. But CBPR should not be undertaken simply out of opportunism and self-interest without the accompanying values and skills necessary to make it an ethically viable and beneficial partnership.

- *Opportunism and self-interest* on the part of *researchers* can drive the interest in CBPR. Examples of this might include:
  - Need for grant funding to support one's academic position
  - Need to recruit individuals from underserved populations as research subjects
  - Need to demonstrate a community partnership to meet funding agency requirements
- *Opportunism and self-interest* on the part of *community members* can drive the interest in CBPR. Examples of this might include:
  - Need for credibility that may come with an academic affiliation
  - Need for a job
  - Need for grant funding to support or sustain community programs

### II. Do you and your team have the necessary skills?

CBPR requires a different set of values, skills and time frame than most research endeavors. Conducting research with underserved communities brings to the fore issues of power, race, class, communication and respect. Specific skills that facilitate building relationships between researchers and communities include:

- **Cultural Competence** – a set of knowledge, skills, and attitudes that allow individuals, organizations and systems to work effectively with diverse racial, ethnic, religious, and social groups.
- **Communication** – the ability to provide and receive ongoing feedback with community partners throughout the life of the research project, in ways that are meaningful and accessible
- **Listening** – can receive feedback and insights from both community partners and researchers about research methods and approaches. On the researcher's end, being a skillful listener requires recognition that you do not have all the answers and that there may be other ways to conduct the research that may be more amenable to the community; as a community member, one should recognize and respect the researchers' expertise in different methods and their outcomes
- **Sharing power and control over decisions** – many researchers arrive in a community with a set protocol and are unwilling to make changes or share decision-making about methods and approaches with non-researchers. If individuals on your research team do not possess these skills, or are not comfortable with developing these skills, then pursuing a CBPR project is not for you. Similarly, community members cannot expect to have "veto power" on the research project's methods and design simply because they "know the community best." Working through consensus or majority decision-making processes are critical for successful partnerships, and these methods are not suitable to all personalities or stakeholders.

### III. Are you as a researcher uncomfortable with changing your methods and/or approach to working with participants?

CBPR involves a set of core principles that include a commitment: to the co-learning process and involving

the community in every step of the process. While on the surface, this may sound agreeable to a researcher interested in CBPR, we encourage researchers to reconsider this approach if:

- You might find it challenging to participate in a co-learning and reciprocal research relationship, especially if it means using different research approaches and methods that you are less familiar with
- You are more comfortable with a linear approach to research (i.e., not iterative or cyclical)
- You find yourself questioning the validity and reliability of CBPR study designs
- You are uncertain or skeptical about the scientific objectivity of CBPR research findings
- Your academic institution does not hold credence in CBPR, so work in this field may significantly reduce your opportunities for tenure and/or promotion
- You have concerns about achieving measurable results and changes in health outcomes within the longer timeframe often required in CBPR study designs, i.e., it takes too long to show results

#### **IV. Are you a community member who simply wants an intervention or community service but who has no interest in research questions?**

If, as a community member, your primary interest is only on services and local interventions, then participating in a research project may not be for you. Community service projects have different timelines and overall goals and objectives, compared to a research intervention. If you are unable to agree to the research goals and objectives, then participating in a CBPR partnership would likely be frustrating.

#### **V. Do the ethical considerations related to burden and benefits to the community outweigh potential research benefits?**

Before beginning a CBPR project, carefully consider the potential benefits and harms of both the process and the outcome to the community of interest. Specific elements to consider include:

- **Time** - do you as a researcher or community partner have adequate time to invest in developing a CBPR partnership? It takes time to develop relationships, build trust, create modes of operation, and identify community assets. A rushed or half-committed approach to building the partnership is likely to fail – therefore, knowing in advance that you do not have time to invest in the process raises ethical considerations of raising expectations.
- **Burden on the community** – many communities in close proximity of universities are accustomed to being the subject of research studies. The participatory methods involved in CBPR require significant time and energy on the part of community members. Repeated CBPR studies in a single community can create a fatigue factor if tangible results are few and far between.
- **Research objectives and anticipated results will/may provide minimal benefit to the community** – a study that produces interesting results for science but limited results for those participating in the study can be problematic if community expectations have been raised through the CBPR process for more direct, tangible results. Clear communication about realistic, potential research outcomes can off-set this potential harm, but it is also critical to assess and re-assess community expectations throughout the research process, in order to prevent any possible negative effects.

#### **VI. What if you don't "buy into" the values and principles of CBPR?**

Not every researcher will agree with many of the values and principles that form the foundation of CBPR. If these values and principles don't fit you, then don't force the square peg into the round hole. So before going forward re-consider the following:

- **Do you have a clear community of identity to work with?** Have the people you've called a "community" really see themselves this way?

- **Do you believe that attending to social inequities should be part of a research agenda?** You may worry that this objective clouds the research process and could reduce objectivity and the integrity of the research design.
- **Do you question the need to address health – and therefore your research – from an ecological perspective?** Taking an ecological perspective requires examining determinants of health from more than one ecological level (e.g., individual, interpersonal, community, organization or policy). By definition then this would require a more complex research design requiring objectives at more than one ecological level.
- **Do you perceive community participation as exploitative rather than empowering?** There is no doubt that there is the potential for this to happen and past experience shows examples of communities being “used” with little change achieved in their health, social, or economic status at the end of a research project. It can also be a burden to the researcher to assure that the process is not becoming exploitative.
- **Are you committed to a participatory process, to community participation in the entire research process, and to delivering meaningful value and benefits to the community?**

## Unit 1 Citations

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## Unit 1 Recommended Resources

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. (1998 (with 2000, 2002 and 2005 amendments)). *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. <http://www.pre.ethics.gc.ca/english/policystatement/policystatement.cfm>

Community IRB Member: Neighbor and Partner. This US Department of Education website has information geared towards community members who are serving on institutional IRBs. <http://www.orau.gov/communityirb>

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*Protecting Human Subjects Newsletter*, published by the US Department of Education: Issue focused on CBPR available at <http://www.science.doe.gov/ober/humsubj/fall03.pdf>

Research Ethics Tip Guide: [http://www.uml.edu/centers/CFWC/programs/researchethics/research\\_ethics1.htm](http://www.uml.edu/centers/CFWC/programs/researchethics/research_ethics1.htm)

*Research Ethics Training Curriculum for Community Representatives* (RETC-CR): Family Health International's Office of International Research Ethics has developed a dynamic and innovative curriculum to empower community representatives through training and education to act as a competent voice for research participants worldwide. Developed and field-tested in eight countries, the RETC-CR helps community representatives to understand the research process and their roles and responsibilities as partners of the research team. The Curriculum also explains the corresponding roles and responsibilities of Ethics Committees/IRBs and Researchers. <http://www.fhi.org/en/RH/Training/trainmat/ethicscurr/retccr.htm>

Research Ethics Website provides course development, training, educational resources and case study development on improving research ethics in environmental health. Proceedings are available from the project's 2003 national conference on research ethics and CBPR. <http://www.researchethics.org>