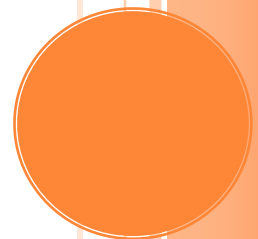




Inspiring Change

Workbook

A community-based participatory research workbook for involving African Americans with serious mental illness in research



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PREFACE

Welcome to community-based participatory research (CBPR)! The Inspiring Change workbook will help guide you on your journey. All members of the CBPR team will have this workbook and complete activities during meetings.

People with severe and persistent mental illness such as depression, anxiety, posttraumatic stress disorder, bipolar disorder and schizophrenia often have challenges with accessing health services and staying healthy. Cultural differences and discrimination can create additional health care barriers for African-Americans with serious mental illness. **This workbook was created to address these health care obstacles by involving Blacks/African-Americans with mental illness in all stages of the research process.** We strongly believe that this approach makes for stronger research projects: projects that explore important problems and make significant changes in the community.

The activities in this workbook are designed for CBPR members who have little formal research experience. The project leadership will consist of one African-American with serious mental illness, one health service provider, and one researcher. The leaders will have an Inspiring Change manual in addition to this workbook and will use the manual to guide the project.



Welcome to
Community-Based
Participatory
Research!

The leadership has already met to identify a research topic and recruit a CBPR team (including you!). During the first CBPR meeting, the leaders will talk more about your specific project and answer questions that you have. As an introduction to CBPR, you can complete Chapter 1 of the workbook on your own before the first session. As a CBPR team member, you will keep a copy of this workbook and bring it to each meeting. Together as a team, you will work through the workbook activities in Chapters 2-11 during regular meetings. Your leaders will tell you which sections you will be working on for each meeting and will provide an agenda to structure your group meetings.

About the Manual and Workbook

In the creation of this manual and workbook, the Training and Development Advisory Board (TDAB) met weekly for nearly a year. The TDAB consisted of eight African-Americans with serious mental illness, two researchers, and three community health providers from urban Chicago. We used multiple sources to guide this project and are ever thankful for past research upon which we based our work. We are also thankful for financial backing from Patient-Centered Outcomes Research Institute (PCORI) and for Illinois Institute of Technology and Chicago Health Disparities for their support of the project.

We hope that this workbook will make the transition to CBPR easier and more accessible for all. Congratulations on your new endeavor and we wish you continued success on your quest!

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Chapter 1: Getting Started

The leadership for your community-based participatory research (CBPR) project has already completed Chapter 1 of the leadership manual in preparation for your project. The leadership will have done the following before the first CBPR meeting:

- Learned about CBPR
- Chosen a research topic and gathered background information on the topic
- Divided up responsibilities among the leadership
- Recruited you and the rest of the CBPR team
- Made plans for the first meeting
- Developed relationships with community partners
- Started a timeline for the project

The leadership will provide you with details of the project during your first CBPR meeting.

Although the majority of activities in this manual will be done as a group, as you get started, reflect on your hopes for the project by answering the following questions.

How might this project help you grow as a person?

How might this project help you grow professionally?

What motivated you to be involved in this project?

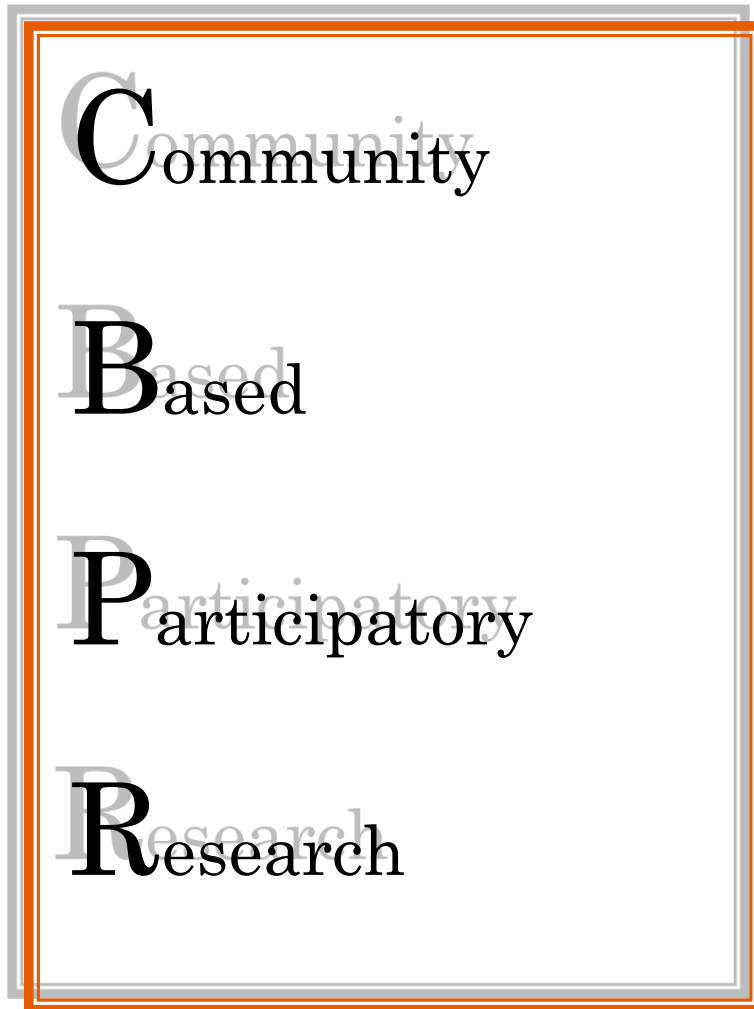
What do you hope to accomplish during this project?

Chapter 2: Introduction to Community Based Participatory Research (CBPR)

Your project leadership will walk you to this chapter during your first CBPR meeting.

Chapter Goals

- Understand CBPR definition and principles.
- Learn about basic research concepts.
- Explore chosen research topic.
- Build rapport within the team.



Worksheet 2.1: Introduction to Community-Based Participatory Research

Read the definition of CBPR below and write down what strengths you bring to the team.

Community-based participatory research (CBPR) is a **collaborative** approach to research that involves all partners in the research process. This research format recognizes the **unique strengths** that each partner brings. CBPR begins with a research topic of **importance to the community**. CBPR combines knowledge and action for social change to **improve communities** and **eliminate disparities**. (Adapted from W. K. Kellogg Foundation's Community Health Scholars Program, 2001, p. 2)



What strengths do you bring to your CBPR team?

Worksheet 2.2: Community-Based Participatory Research Principles

Review the principles of CBPR that have been adapted from Minkler & Wallerstein, (2008). Discuss how you think these principles will apply to your project.

CBPR Principle	Questions For Your Project
1. CBPR brings researchers and community members together during all parts of the research process	How can all group members become involved?
2. CBPR balances research <i>and</i> action for the benefit of all partners	What actions might come out of your research?
3. CBPR recognizes the community as a whole	How do you define your community for this project?
4. CBPR uses the opportunities and talents within the community, recognizing that everyone has something to offer	What are the opportunities and talents in your community?
5. CBPR allows researchers and community members to learn from each other and get results	What do you hope to learn from the community/researcher?
6. CBPR is a long-term process that requires commitment and dedication	What type of commitment and dedication do you expect from each team member?
7. CBPR focuses on issues in the local community. CBPR pays attention to the many factors that contribute to those issues.	What issue in your local community will you be addressing? What factors impact it?

CBPR Principle	Questions For Your Project
<p>8. In CBPR, community research partners share information obtained from the research for the benefit of all people involved</p>	<p>Who will benefit from your research?</p>
<p>9. CBPR tries to improve the health care system through open and consistent communication between researchers and the community</p>	<p>How will your project improve the health care system?</p>
<p>10. CBPR promotes the rights of community members to make their own choices and in many ways empowers all persons involved in the process.</p>	<p>How can leaders empower group members? How can group members become empowered? How can this project empower the larger community?</p>

Worksheet 2.3: Research Process Worksheet

Read and discuss the steps of the research process with your team.



*Research is to see what
everybody has seen and think
what nobody has thought.*

--Albert Szent-Gyorgyi

Worksheet 2.3: Research Process Worksheet (continued)

Now for each step of the process, give examples of how your project might complete each step. You will discuss each of these in more detail during later team meetings, so right now just discuss a few examples to help understand the research process.

Step in Research Process	Example
<p>Research Question Decide what you want to find out or what you want to test</p>	<p><i>e.g. - Why do people with diabetes miss doses of medication?</i> Your project:</p>
<p>Method Decide how you will answer the research question</p>	<p><i>e.g. - Questionnaire/survey of people with diabetes</i> Your project:</p>
<p>Data Collection Go out in the field and gather the information.</p>	<p><i>e.g.- Give out the survey at local community centers</i> Your project:</p>
<p>Analysis Look at the information you have gathered and decide what it means</p>	<p><i>e.g.- Enter the information in the computer to see the most common reasons for not taking medication</i> Your project:</p>
<p>Dissemination Share the information/results with others</p>	<p><i>e.g. - Tell doctors/clinics that people don't understand the directions on their medications</i> Your project:</p>
<p>Action Use the information/results to make changes in the world</p>	<p><i>e.g. - Develop a program that will help diabetic patients take their medications</i> Your project:</p>

Worksheet 2.4: Roles & Responsibilities

Many different people can be involved in CBPR projects. Projects that address health needs of African-Americans with serious mental illness may include the team members that fill the following roles and responsibilities.

Read the roles and responsibilities and discuss who fills which roles for your project.

Persons with Lived Experience. Persons with lived experience involved in CBPR projects bring a perspective that cannot be learned in a classroom. For this project, people with lived experience are African-Americans with a diagnosis of serious mental illness. People with lived experience are on the front line of issues that affect their lives. To conduct community based research without this much-needed perspective would be useless.

Researcher. The Researcher is essential in the CBPR process, especially in the collection, organization and analysis of data. The researcher adds credibility to the project and makes sure the project is feasible. Also, the researcher gets Institutional Review Board (IRB) approval for the project.

Project Lead. The Project Lead is the member of the leadership who makes sure the project gets done and delegates tasks as needed.

Community Organization. The Community Organization has the resources in the community to carry out the project, share the findings and keep the project going once the funding has ended.

Healthcare Provider. The Healthcare Provider can identify problems in the health systems and understand how solutions can be implemented in the community structure. Providers have connections with community organizations that can assist the project.

Other Roles. Some teams may identify others who will be important to their specific project. These could include family members, insurance providers, religious/spiritual leaders, etc.

Chapter 3: Working Together

Working together on a CBPR project can be challenging. Your team will need to make decisions, communicate effectively and manage conflicts within the team. The activities in this chapter are designed to help your team improve communication and address problems that may arise.

Chapter Goals

- Develop group rules.
- Establish a group decision-making process.
- Discuss challenges and solutions for group work.



Worksheet 3.1: Group Decision-Making

There are several ways to make decisions in a group setting. Read the descriptions of each decision-making type and discuss pros and cons of each.

- **Consensus:** the group discusses each possible option and agrees to support the decision in the group interest
- **Majority vote:** the group takes a vote of all present, and the decision with the most votes is chosen
- **Leaders' decision:** the leaders of the group will make an executive decision

	Pros	Cons
Consensus		
Majority vote		
Leaders' decision		

Worksheet 3.2: Working Together

Read the descriptions after each heading and discuss the questions in italics.

Handling Conflicts

In any group, conflict happens. It is the group leaders' responsibility to keep order and manage conflicts. Also, individual group members have a responsibility to come to group prepared to work in the best interest of the project. Group leaders are available to support group members both individually and in the group setting so that they can manage conflict and keep focus on the project.

What are some ideas about how we can handle conflicts within the group?

Making Reasonable Accommodations

Accommodations are supports or allowances that are provided for group members to help them participate and be included despite barriers that they may have. Allowing a group member to take a 'time out' if he/she is feeling anxious is one example of an accommodation. Accommodations might be needed because of serious mental illness, physical illness or other special unforeseen circumstances (death in the family, work obligation, etc.). Here are some accommodations that might be needed by people with serious mental illness.

- Excused absences for emergency doctor or therapy appointments.
- Leaders being available before and after group to provide support on managing conflicts, problems or stress.
- Reminder calls for meetings.
- Scheduling shorter meeting times.
- Allowing extra breaks.

The group leaders will not always know that you need an accommodation. Please think about whether an accommodation would allow you to be more comfortable or to contribute more to the group. If you feel comfortable asking for accommodations in a group setting, please do so, or you can speak to someone in the leadership individually. You should also be understanding if others in the group need accommodations. Accommodations should not be seen as "special treatment," "playing favorites" or "dumbing down." Accommodations simply create a level playing field.

Do you have any questions about accommodations? Are there other accommodations that you can think of?

Dual Relationships

Members of the CBPR team may have personal or professional relationships outside of the group. This is called a dual relationship. For example, there might be a health care worker and client from the same agency working together on the research team. Just because two people have a dual relationship with one another, does not mean they should not work together on the team. The two individuals might want to meet with the leadership to talk about how the dual relationships might impact their group work. These relationships should be addressed on an individual basis, keeping in mind that each person should be respected as individual. People with lived experience should feel that their participation in this project, will have no effect on their mental or physical health services within the community agency. Health care workers should be able to work with clients on the project on an equal playing field.

What are some dual relationships that team members might have? How do you think these could change the way they think or act?

Power Dynamics

Sometimes, people with lived experience feel that health care providers or researchers have more knowledge or resources and they (people with lived experience) have little to offer. In CBPR, all perspectives are valued and all group members should be treated equally. Health care workers or others on the team (e.g. family members) should be willing to relate to other group members on an equal basis.

How can we make sure that power is shared equally?

Small Group Work

Your team may wish to break into smaller groups to accomplish specific tasks. Small groups make individual members more accountable and committed to the project and can be more efficient. Small group work should be started only after the group has met together for a number of times and has become familiar with the project and the other group members. The small groups should be carefully formed so that strengths and weaknesses are balanced within the groups. The tasks of the small groups should be well-

defined so that group members know exactly what they are supposed to accomplish. All work done in small groups should be presented to the larger group upon completion.

What tasks might you want to use for small group work on your project?

Changing Members

Although all group members committed to the project, plans change and one or more group members may have to leave the group in the middle of the project.

If a group member had to leave, would you replace that member? Why or why not?

Are there situations in which you would ask a group member to leave?

Who would be responsible for asking the member to leave?

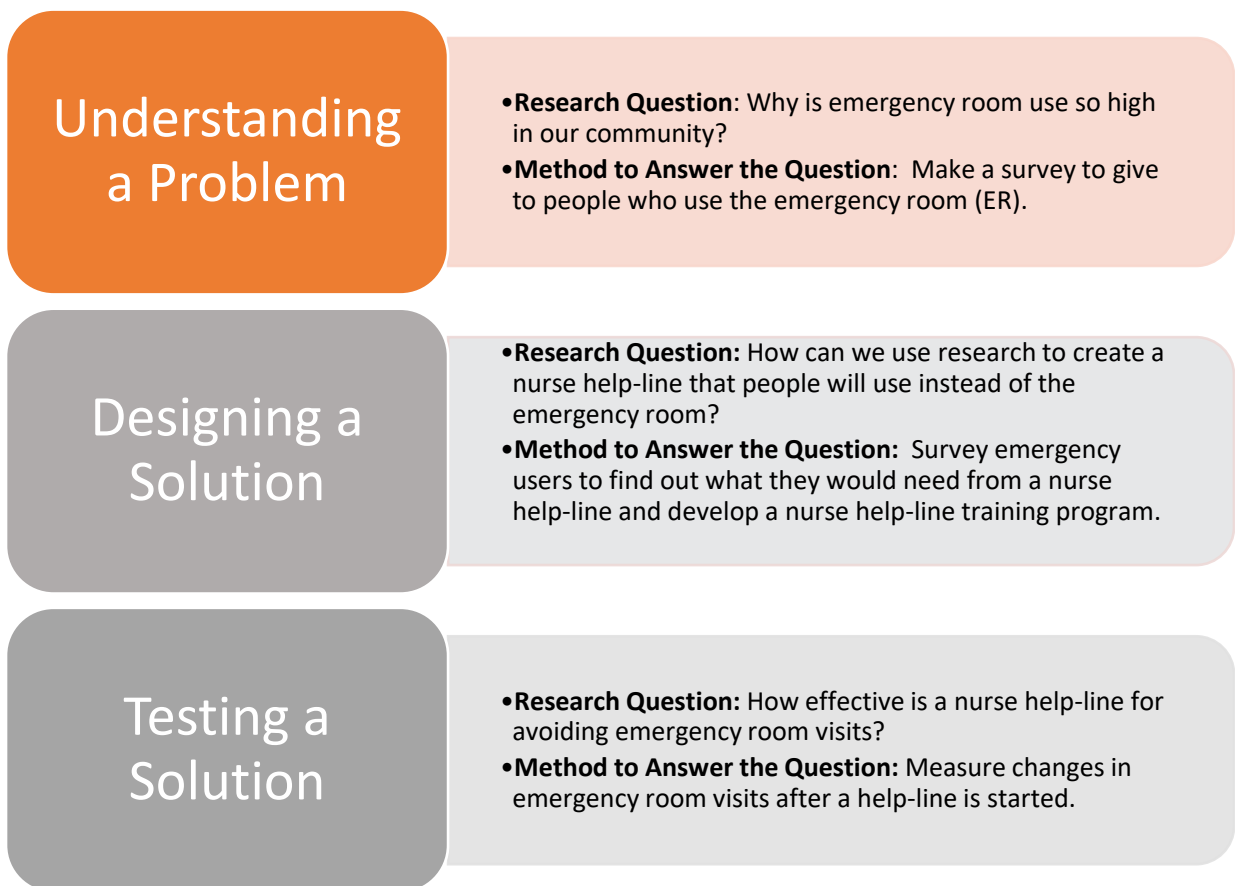
Chapter 4: Understanding a Problem

The purpose of this chapter is to develop your topic idea. Your team will complete this chapter only if you are doing research to understand a problem. After completing this chapter you will skip to Chapter 7. If your research is designing a solution, go to Chapter 5. If your research is testing a solution, go to Chapter 6.

Chapter Goals

- Gain understanding of basic research types.
- Discuss chosen research topic.
- Introduce research methods.
- Select research methods.

In the figure below are the three main research types. Discuss these as a group and ask any questions you may have.



The problem that we want to understand is:

Project Example for Understanding a Problem

Read the description of a CBPR project that aims to “understand a problem.”

A CBPR team wants to learn about the problems that homeless African-Americans with serious mental illness have with getting health care. The team decided to focus on the Edgewater/Uptown neighborhood because there is a large homeless population there.

Drawing on their own experiences of homelessness, the CBPR team created a list of questions to ask their research participants. The team handed out flyers in the neighborhood to find recruit participants for focus groups. During the focus groups, homeless African-Americans with serious mental illness talked about their experiences with the health care system. A research assistant recorded what the focus group members say and then the researcher analyzed the information.

The researcher gave a summary of the focus group results to the team. The team discussed the results and decided what they want to do next. They decided to share the results with hospitals or social service agencies in the neighborhood to create better services. They also brought the results to lawmakers to explain the needs of the community.

What was the problem that the CBPR team wanted to understand in this example?

What method did the CBPR team use to understand the problem?

Are there other actions that the team could take after they have the results of their research?

Research Methods for Understanding a Problem

There are many different ways to understand a problem. Read and discuss each one with your team.

Key Informant Interviews

In key informant interviews, the researcher has a question and answer sessions with an expert in a given field. This expert can be a professional and/or a layperson. Examples of key informants are professors, community activists, or health care workers.

Focus Groups

Focus groups are question and answer sessions conducted in a group format. A small group (usually 6-12 people) meet for an hour or two to discuss their experience with a specific topic. For example, to find out why the dropout rate is high in the community, a researcher might invite young Black teens to talk about their reasons for leaving school.

Surveys

Surveys are written question and answer documents that have a specific theme and objective. Surveys are quick and easy tools used by researchers to collect and analyze data. An example of a survey question is: How many times in the last week have you gone to the doctor?

Observation

Observation is a research method that studies participants in their natural environment engaging in natural situations. An example of observational research would be counting how many times someone picks up a medication refill from the pharmacy.

Windshield Tours

Windshield tours are community field trips used to collect data and/or get a general feel for the neighborhood and the chosen problem. For example, if your research team wants to understand health care in nursing homes, you might tour several nursing homes.

Worksheet 4.1: Choosing a Research Method to Understand a Problem

Fill in the chart below to evaluate research methods for your project.

Method	Benefits	Risks and Challenges	Use for our project? Yes/No
Key Informant Interviews			
Focus Groups			
Surveys			
Observation			
Windshield Tours			
Other			

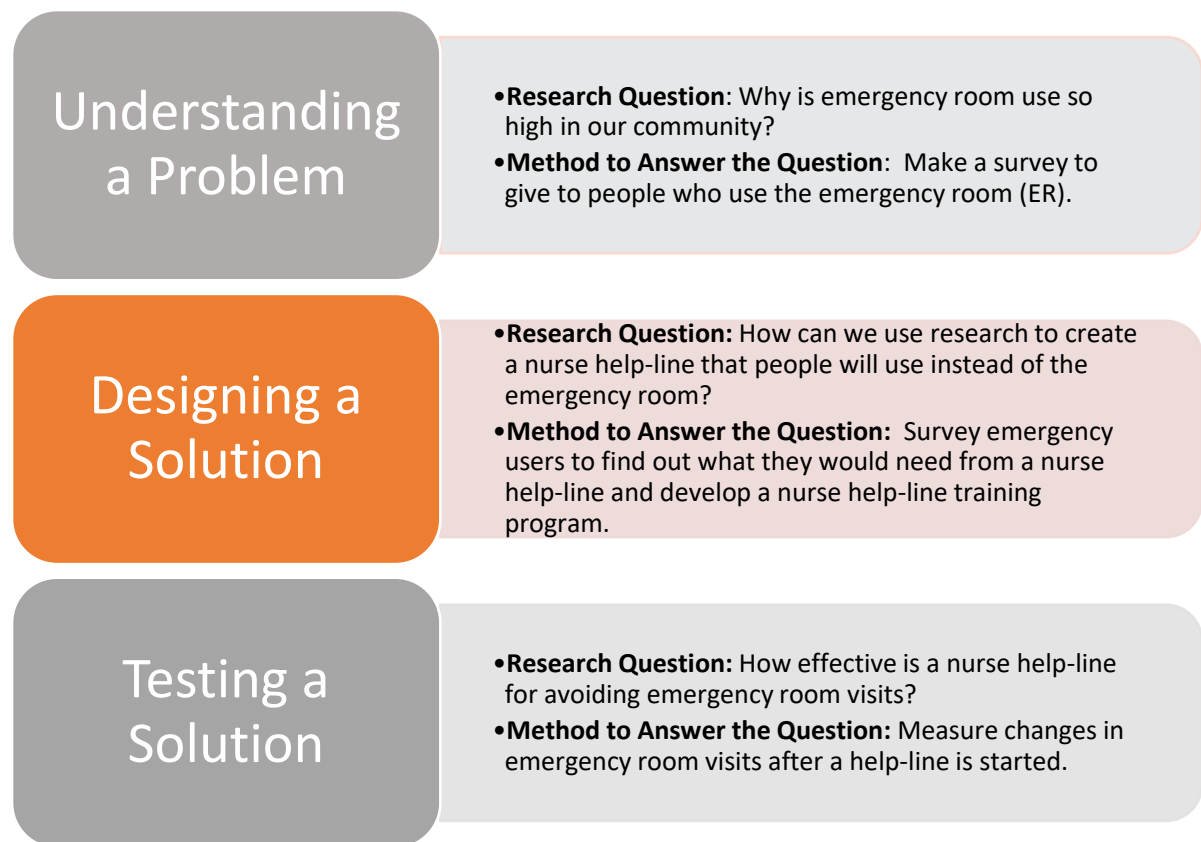
Chapter 5: Designing a Solution

The purpose of this chapter is to develop your topic idea. Your team will complete this chapter only if you are doing research to design a solution. If your research is designing a solution, you will skip Chapters 4 and 6.

Chapter Goals

- Gain understanding of basic research types.
- Discuss chosen research topic.
- Review research literature.
- Learn about research methods.
- Design a solution.

In the figure below are the three main research types. Discuss these as a group and ask any questions you may have.



The solution that we design will help:

Worksheet 5.1: Designing a Solution

Use this worksheet to design your solution. The examples in the right-hand column are provided as a guide. As a group, fill in the answers for your project and record on a separate sheet of paper.

<p>What is your specific problem?</p>	<p><i>Example: Black youth transitioning from foster care don't want to use traditional mental health care</i></p>
<p>Who exactly is your solution/project trying to help? Will you focus on people of a specific age, gender, diagnosis, neighborhood, etc.?</p>	<p><i>Example: Black youth with any mental illness ages 18-24 who are transitioning out of foster care on the south side of Chicago.</i></p>
<p>How exactly will your solution/project be carried out? Will it be a group training, pamphlets distribution, online, door-to-door, etc.?</p>	<p><i>Example: Our solution/project is a one hour weekly peer support group consisting of 8-10 youth that will last for 6 weeks.</i></p>
<p>Who will carry out the project?</p>	<p><i>Example: Our CBPR team will first design the curriculum for the weekly sessions and write a training program for youth leaders, "Community Organization A" will train the youth leaders, and youth leaders will facilitate the groups.</i></p>
<p>What credentials or qualifications will be needed for the people carrying out the project?</p>	<p><i>Example: The youth leaders must be under age 30, have lived mental health experience, have been in foster care system, and must complete a training certificate program</i></p>
<p>In what settings will the project take place? (ex-community organization,</p>	<p><i>Example: The youth leaders will be trained at "Community Organization A." The peer support groups will be held at local park district meeting rooms.</i></p>

church, shopping center, etc)	
How will you evaluate the pilot? That is, how will you know if it's working?	<i>Example: We will interview the youth leaders and trainers. We will give participants a survey about their satisfaction with the program. We will look at participant attendance/drop-out in the group sessions</i>
Given the time limits that you have, do you think you can complete this project (including a pilot test)? Give a rough timeline here.	<i>Example: Yes, we have 9 months. Month 1-4 we design the solution, Months 5-6 we recruit and train youth leaders for the pilot test. Month 7-8 the youth leaders lead their groups. Month 9 we evaluate and report the results.</i>
Besides your CBPR team members, how many people will you need to design and pilot test this solution? List them here.	<i>Example:</i> <i>1 staff person from "Community Organization A" to hire and train the two youth leaders</i> <i>2 youth leaders</i> <i>20 youth with mental illness to participate in the peer support groups</i>
How will you find the people you will need for this project (patients, providers, etc)?	<i>Example: We will recruit through "Community Organizations A, B & C" for youth leaders and participants. We will pass out flyers in park districts and community centers. We will ask the CEO of Community Organization A for a recommended staff member to train the youth leaders.</i>
How will you keep participants engaged in this project?	<i>Example:</i> <i>1. pay youth leaders and staff person for training and supervision</i> <i>2. Give agency awards/ recognition for the youth leaders and staff person</i>

	<p>3. Give completion certificates to peer group participants</p> <p>4. Provide snacks and drinks at peer groups</p>
<p>What costs will you have for this project? List major costs/ expenses here and estimate amounts. Never underestimate costs!</p>	<p><i>Example:</i></p> <p><i>“Community Organization A” staff member</i> <i>10 hours of training at \$25/hour</i> <i>6 hours of supervising at \$25/hour</i> <i>= \$400</i></p> <p><i>Youth Leaders</i> <i>10 hours of training at \$15/hour</i> <i>6 hours of group at \$15/hour</i> <i>6 hours of preparation and supervision at \$15/hour</i> <i>= \$660</i></p> <p><i>Snacks for Group</i> <i>\$10 per group for 6 groups = \$60</i></p> <p><i>Recruitment Flyers = \$80</i></p> <p><i>Total = \$1,200</i></p>
<p>Do you personally know of people that would be interested in participating in this project? If so, list here.</p>	<p><i>Michael knows a staff member at “Community Organization A” that might be interested in being the trainer</i></p>
<p>How likely is it that this project could be continued long-term or after the original grant money is gone? Explain your answer.</p>	<p><i>The project would be likely to continue because its low cost and “Community Organization A” has already trained the youth leaders, so the only costs would be to pay them for each group they lead.</i></p>

Worksheet 5.2: Strengths and Challenges

Identify the strengths and challenges at each stage of the process in the spaces provided below.

	Strengths	Challenges
Designing the Solution	<i>e.g.- Our CBPR team are young adults and will know what will appeal to young people</i>	<i>e.g.- Our CBPR team doesn't have much time to write the curriculum</i>
Recruiting Participants	<i>e.g. - our CBPR team knows a lot of health care workers and young adults that we can pass out flyers to</i>	<i>e.g. - participants might need transportation, childcare, have trouble reading, not want to attend because of stigma</i>
Evaluating the Project	<i>e.g. - "Community Organization A" has agreed to let us interview people at their location.</i>	<i>e.g. - We can't attend group sessions to observe how they are going because it would be too disruptive</i>

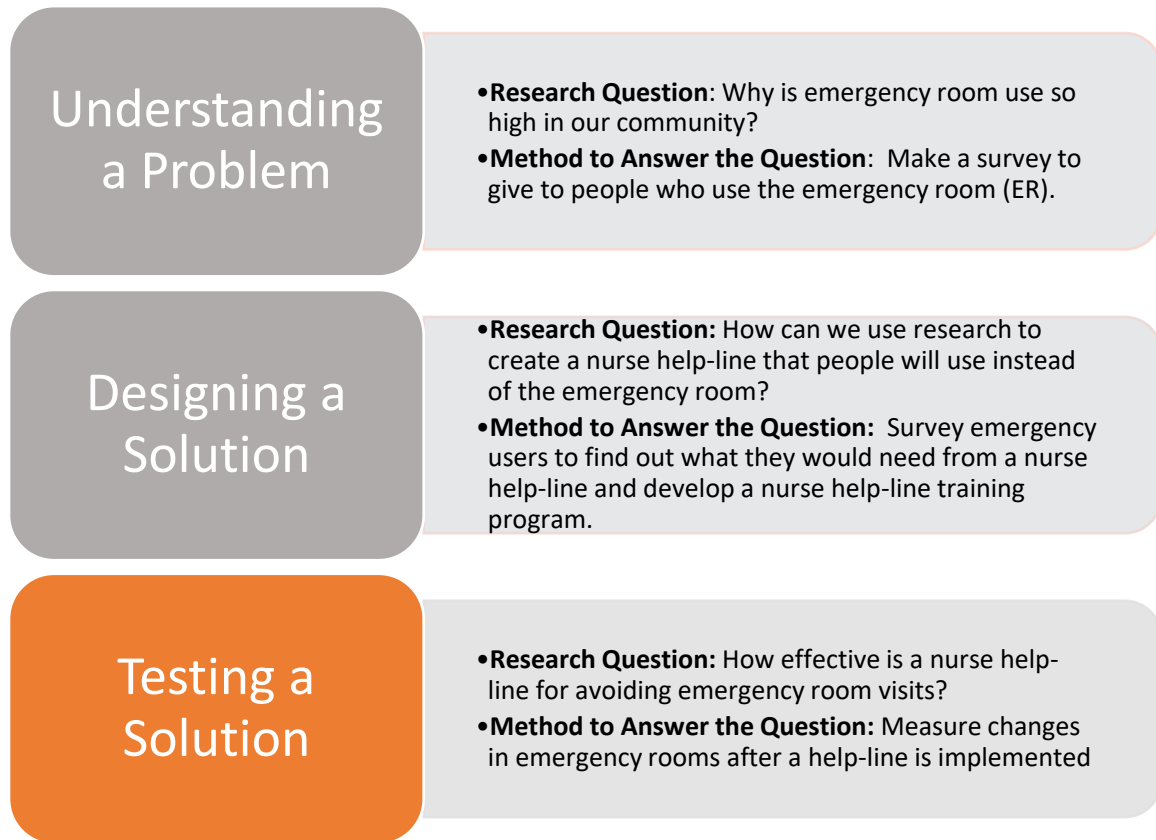
Chapter 6: Testing a Solution

The purpose of this chapter is to develop your topic idea. Your team will complete this chapter only if you are doing research to test a solution. If your research is testing a solution, you will skip Chapters 4 and 5.

Chapter Goals

- Gain understanding of basic research types.
- Discuss chosen research topic.
- Identify outcomes to test.
- Learn about research methods.
- Develop a plan to test a solution.

In the figure below are the three main research types. Discuss these as a group and ask any questions you may have.



The solution that we will test is:

Worksheet 6.1: Identifying Outcomes

Talk about answers to the following questions and write your ideas here:

Our Solution/ Intervention is:

1. How might this solution help people?
2. How might this solution hurt people?
3. What might be other benefits of this solution?
4. What might be barriers to this solution working?

Research Methods for Testing a Solution

There are many different ways to understand a problem. Read and discuss each one with your team.

Surveys

Surveys are written question and answer documents that have a specific theme and objective. Surveys are quick and easy tools used by researchers to collect and analyze data. An example of a survey question is: How many times in the last week have you gone to the doctor?

Observation

Observation is a research method that studies participants in their natural environment engaging in natural situations. An example of observational research would be counting how many times someone picks up a medication refill from the pharmacy.

Interviews

In key informant interviews, the researcher has a question and answer sessions with an expert in a given field. This expert can be a professional and/or a layperson. Examples of key informants are professors, community activists, or health care workers.

Focus Groups

Focus groups are question and answer sessions conducted in a group format. A small group (usually 6-12 people) meet for an hour or two to discuss their experience with a specific topic. For example, to find out why the dropout rate is high in the community, a researcher might invite young Black teens to talk about their reasons for leaving school.

Randomized Controlled Trial

In a randomized controlled trial there are two groups of participants; one group of participants gets the solution/intervention and the other group of participants does not. Participants are randomly assigned to one of the groups. This type of research is the best way to scientifically test a solution.

Fidelity Measures

Fidelity measures find out whether the solution/intervention was carried out correctly. For example, if the solution/intervention is a training program, fidelity measures test whether the trainers covered all the material that was supposed to be covered in the training. The fidelity measure is usually a checklist that details each part of the intervention.

The researcher observes the intervention and checks off the parts that are completed.

Feasibility Measures

Feasibility measures test whether the solution/intervention is practical and can be carried out. Feasibility usually includes looking at costs versus benefits of the solution/intervention.

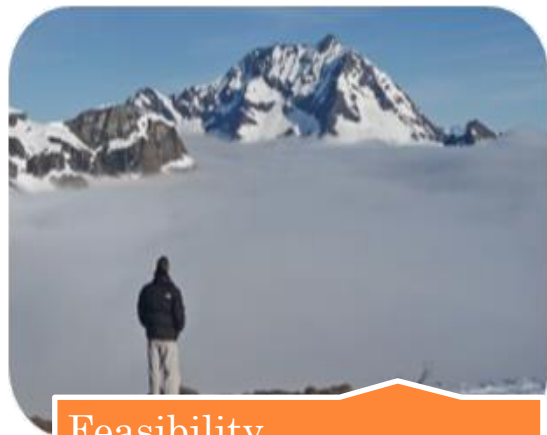
Research Method Summary

Surveys	List of questions on paper or computer
Observation	Watch people in their natural environment and keep records of their behavior
Randomized Trial	Give only half the participants the solution and see if they do better than the others
Focus Groups	Ask people open-ended questions in a group setting
Interviews	Ask open-ended questions to individuals



Fidelity

- How well were the directions followed?



Feasibility

- Can the project be done with the given resources?

Worksheet 6.2: Choosing a Research Method to Test a Solution

Fill in this matrix to help guide your decision on research methods. Think about costs and time requirements as well.

	What does it test?	What are the advantages and disadvantages?	Use? (y/n)
Surveys			
Observation			
Interviews			
Focus groups			
Randomized Controlled Trial			
Fidelity Measure			
Feasibility			

Worksheet 6.3: What Do We Need?

Fill in your chosen research methods in the left column. Then list the steps and resources that you will need.

Research Method	Steps Needed	Resources Needed
<i>Example:</i> <i>Focus Groups</i>	<i>Example:</i> <ul style="list-style-type: none"> • <i>Write interview questions for the focus group</i> • <i>Find meeting room</i> • <i>Figure out how to pay participants</i> 	<i>Example:</i> <ul style="list-style-type: none"> • <i>Meeting space with 10 chairs and table</i> • <i>Gift cards to pay participants</i> • <i>Research assistant to transcribe focus group</i>

Chapter 7: Research Ethics

In this chapter you will learn about research ethics for social science research.

Chapter Goals

- Define research ethics.
- Learn about historical unethical research.
- Understand ethical principles of research.
 - Beneficence
 - Respect for Persons
 - Justice
- Evaluate chosen project in terms of ethical principles.

What is Research Ethics?

Research ethics are **moral rules** and **professional codes** that guide the research process.

What are some ethical problems that could happen in research?



Examples of Historical Unethical Research

There have been historical cases of unethical research that have contributed to how we work with participants today.

Nazi Experiments

The history of research ethics begins with the tragic history of research abuse by Nazi doctors during World War II. A total of sixteen German physicians practiced unethical medical experiments on the Jewish people, political prisoners, and other marginalized groups.

The Tuskegee Syphilis Study

In 1932, the Tuskegee Syphilis Study was a 40-year project administered by the US Public Health Service in Macon County, Alabama. The American Government promised 400 men free treatment for “bad blood” which had become an epidemic in the county. The treatment was never given to the men and was in fact withheld. The men in the study were not informed of the research design and its risks to them.

Institutional Review Boards (IRBs)

Researchers should not decide whether or not their own research is ethical. IRBs were created to protect the rights and well-being of individual research participants. IRBs are committees that consist of five or more members with varying expertise and diversity. IRBs review and approve research studies. They make sure that ethical principles are followed and they monitor studies to make sure that participants are not harmed.

Three Ethical Principles

In part because of the Tuskegee study, the U.S. government created the Belmont Report. The Belmont report gives 3 ethical principles should be followed in research. We will look more at each of these below by discussing a case study.



Beneficence (Do Good/ Do No Harm)

Definition: Researchers and the IRB are obligated to maximize benefits and reduce risk that might occur from the research study.

Case Study, Part 1 Researchers have decided to investigate ways to address suicide among African-American/Black young adults with serious mental illness. The medication they would like to use is known to decrease suicidal thoughts but increase risk of heart disease. The researchers are willing to pay participants \$100 per visit. The participant files will be kept in the researcher's office in a desk drawer.

Worksheet 7.1: Beneficence

Fill in examples for each component of beneficence.

Beneficence Components	Examples
Expected benefits of research should be greater than expected risks.	
Too much compensation/money may blind people to risks or cause people to lie or conceal information.	
Avoid therapeutic misconception. (Therapeutic misconception is when people think that research is designed to help them.)	
Protect the privacy of participants. (Avoid bothering participants.)	
Protect the confidentiality of participants.	



Respect for Persons

Definition: Individuals should be treated as independent decision-makers. Persons who are not able to make independent choices get extra protections (pregnant women, women who are breastfeeding, fetuses, neonates, prisoners)

Case Study, Part 2:

The young African-Americans in the suicide study are made aware of the risk of heart disease. Several decide to move forward with the treatment, however they are unable to read the consent form. The researchers are aware that the potential participants cannot read. The researchers tell the participants that they don't have much time and have to get started soon.



Worksheet 7.2: Respect for Persons

Fill in examples for each component of respect for persons.

Respect for Persons Components	Definition	Examples
Coercion	Coercion occurs when researchers force or influence participants into being in the study	
Informed consent	An agreement signed by a research participant. The informed consent document tells participants about their legal rights, protections and risks/ benefits of the research. (see three main parts below).	
1. Voluntariness	Participants can decide to stop the study at any time without penalty or loss of benefits.	
2. Comprehension	Participants should understand the informed consent document	
3. Disclosure	Participants should know the purpose, potential risks and benefits, as well as alternatives to participating in research.	

Justice

Definition: Fair procedures and outcomes are used to **select** research participants, and there is a fair distribution of benefits and burdens to populations who participate in research.

Case Study, Part 3

The researchers have decided to recruit participants from a poverty-stricken neighborhood. If the medication that they are testing works, they will be able to sell the medication at a high price all over the U.S.

Worksheet 7.3: Justice

Fill in examples for each component of justice.

Justice Components	Definition	Examples
Individual justice	Researchers should not offer research opportunities only to some who are in their favor or select only 'underprivileged' persons for risky research.	
Social justice	Researchers should make sure they don't select participants because they are easy to find and can be manipulated.	
Selection of participants	The participants should be chosen based on the research question. Research should study people who are in any way affected, can benefit, and will not be burdened by the study.	
Deception	Researchers should avoid deception, although in some cases it may be used, provided that risk is low and the participant is told after study.	

Worksheet 7.4: Project Risk and Benefits

Complete the chart with the risks and benefits for your project. After filling in the table, rate each of the risks and solutions on a 1-5 scale, with 1 = very likely, 2 = somewhat likely, 3 = neutral, 4 = unlikely 5 = very unlikely.

Risks of Project	How likely? 1-5	Benefits of Project	How likely? 1-5
<i>e.g.- person could be retraumatized</i>		<i>e.g.- person could be diagnosed</i>	
Total score		Total score	

How will members of your team make sure your study is ethical?

What is your plan for getting IRB approval? Who will be involved? What are the timeframes?

Worksheet 7.5: Informed Consent Review

Use this worksheet with the informed consent document(s) for your project.

- As a group, read through the consent document(s).

 - Circle any areas in the document that you feel will be difficult for participants to understand.

 - With your group, make recommendations for how you would reword those sections.
1. What might need to be added to the consent document to make sure that participants understand?

 2. What other steps could you take to make sure that participants understand the study that they will be participating in?

Chapter 8: Collecting Data

This chapter provides a brief introduction to data collection and recruitment.

Chapter Goals

- Learn about types of data.
- Develop recruitment and data collection plan.
- Develop plan to engage and retain participants.

Our target participants are:

Types of Data

Data using numbers: The CBPR team would count the number of people visiting the ER in one months' time; The CBPR team would design and give a survey to research participants with instructions to rate answers 1 - 7.

Data using words: The CBPR team would ask research participants to share their ER experiences; The CBPR team would lead a group discussion with research participants about how to improve ER services.

Sometimes researchers use both kinds of data together to understand and address problems.

Recruitment

Recruiting is a process to find participants for research. Research participants are customers, so it is important that we make sure the participants are comfortable and have a positive research experience.

CBPR team members have an important role in the recruitment process as community members. CBPR team members know people in the community and know how the community works, so when we plan for recruitment we will need persons with lived experience and community organization representatives' active involvement.

Exclusions

Research sometimes requires us to exclude some people from participating. For example, if create a survey in English, you may have to exclude people who cannot read English because they would not be able to understand the questions. As a group, think about who you would have to exclude from your study and list them here.

Worksheet 8.1: Recruitment Methods

Use this worksheet to examine the advantages and disadvantages of different recruitment strategies.

Ways to Recruit Participants	Advantages	Disadvantages	Use? (y/n)
<i>Ex- flyers</i>			

Worksheet 8.2: Data Collection

Data collection must be done carefully so we can be sure that the results are correct. The researchers who collect data should be consistent, be able to follow exact instructions and should be properly trained.

Make your data collection plan by answering the following questions.

1. Who will collect your data?
2. How will that person(s) be trained?
3. Who will collect the data if that person is no longer able?
4. How much data will you need to collect? How many participants?
5. Do you need to develop or find questionnaires for data collection?
6. How will it be stored?
7. How will you make sure data is safe, secure and confidential?

Worksheet 8.3: Engaging Participants

Engaging means making the research participant feel comfortable, invested and enthusiastic about the research project.

If you will be interacting with research participation during data collection, it is important to:

- be reliable (be on time and be prepared)
- be pleasant and create positive atmosphere
- give research participants enough information and clear instructions
- have a procedure in place for collecting the data and following up with participants (if needed).

Engagement Plan Activity

Talk about the answers to the following questions.

1. How will the first contact with participants be made?
2. Who will be contacting and scheduling participants?
3. Who will be meeting with participants to collect the data?
4. What incentives will you offer participants?
5. What training do the people doing the data collection need?
6. Are there things about the culture (African-American or other) of participants that the people doing data collection should know or keep in mind?
7. How can you make the research comfortable for your participants?
8. Are there any accommodations (special arrangements) that you would need to make for participants with disabilities or other special circumstances?
9. How can you make sure that interested participants get the results of your research?
10. How can you keep participants interested during the data collection?
11. How will you review the data collection process to make sure that participants are satisfied and that the data is valid?
12. How should the CBPR members be involved in an ongoing basis in data collection?
13. Are there any other thoughts about how to engage participants?

Worksheet 8.4: Retaining Participants (optional)

Retaining means being able to physically connect to and/or contact the original research participants to collect data. This is important if you will need to contact your participants at more than one time.

Retention Plan Activity

Talk about the answers to the following questions.

1. How will you contact participants? (phone, email, etc.)
2. How many times will you need to contact each participant? List specifics here.
3. If participants cannot be reached by the above method, what is the back-up method?
4. Who is responsible re-contacting and tracking participants? Who is the back-up person?
5. What training does this person need?
6. Are there things about the culture (African-American or other) of participants that the people doing data collection should keep in mind?
7. What are other ways you can you keep participants in the study?
8. How many times will you attempt to re-contact people if you are unable to reach them?
9. How can the CBPR members be involved in participant retention?
10. Are there any other thoughts about retention?

Chapter 9: Sustainability

This chapter provides information on project sustainability and guides you in decisions to sustain your project.

Chapter Goals

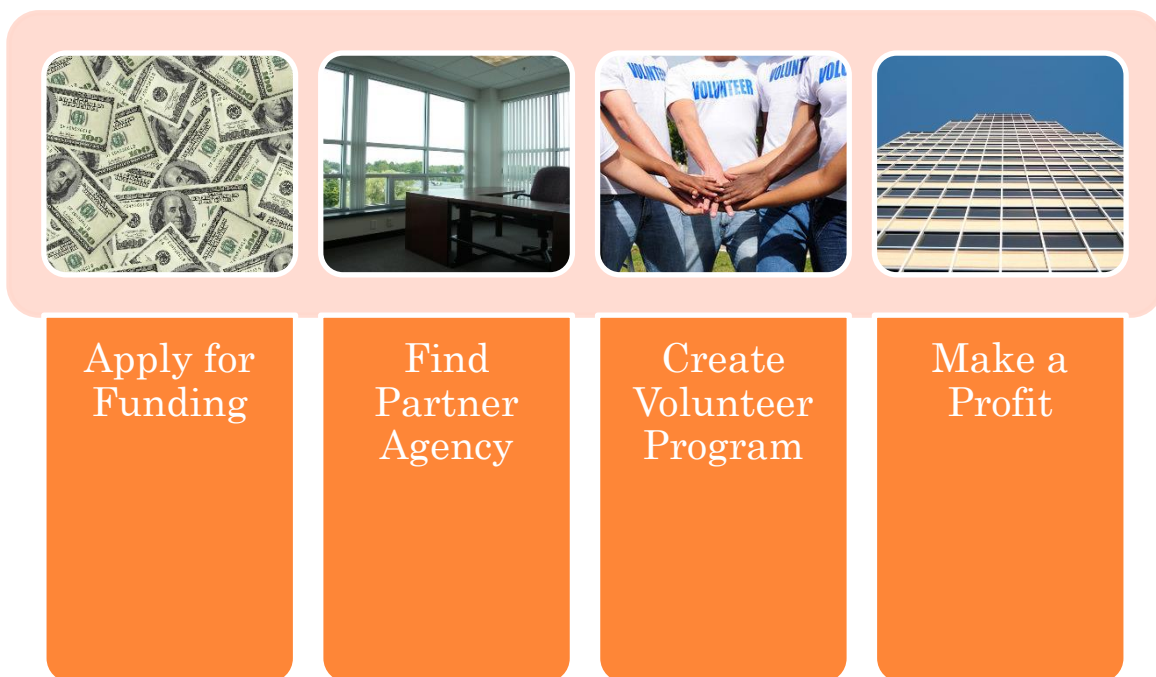
- Learn about option for sustainability.
- Explore ways to sustain your project.
- Discuss pros and cons of sustaining the project.
- Make a sustainability plan.

Sustainability is whether or not a project/program can continue after the original research is complete.

To continue a successful project, the CBPR team must examine their community and find the needed resources. These resources may include: community agencies, professionals, grants or volunteers

In CBPR projects, the research team is expected to take an active role in sustaining the project and making sure the project has an impact in the “real world.”

Here are some ways to create sustainability for your project:



- **Apply for Funding**

- This includes private grants, government grants, asking for donations from private donors and corporations, or fundraising activities
 - Funding takes time, effort and expertise. Researchers will take the lead on writing grants, but often the CBPR team can use their community networks to find small donations or local grants that are easier to obtain.
 - If finding more money is the chosen option, it may be necessary to consult a professional fundraiser or an expert in grant funding to come and talk with the CBPR about options.
- **Find a Partner Agency**
 - Depending on your project, the organization can be a hospital, church, social service agency, clinic, government agency, shelter, etc.
 - If the CBPR team is already working with a community agency, start talking with them about sustainability right away. Work with the partner about ways that the project can increase revenue or reduce costs. For example, projects that reduce emergency room visits may reduce hospital costs or maybe the service that you design can be billed to a health insurance company.
 - If your current community partner cannot or does not want to keep the project active, the CBPR team will seek other organizations to partner with before the end of the project.
- **Create a Volunteer Program**
 - Some projects can have an important and lasting impact on the communities involved, but no funding is available. In this case, CBPR teams can implement a volunteer program or use an already existing volunteer program to continue project goals.
 - For example, if your research found that African Americans with mental illness lack family support while hospitalized, existing hospital volunteers could provide extra companionship for those individuals.
 - The CBPR team itself could create a volunteer program to carry out the project, although this would require a high level of commitment.

- **Make a Profit**

- Private companies and other organizations may be interested in using the results of your research and may be willing to pay for programs that you have created.
- For example, if your project has designed a diversity training program for the workplace, employers might be willing to use your program and hire members of your CBPR or other people with lived experience.

This results in profits for the company, creation of jobs, sustainability of the project and a positive impact on community employees.

- Alternately, your team could copyright your program or develop a business that sells your program to others. To carry this out, you would need someone willing and skilled in business to take the lead.

Worksheet 9.1: Pros and Cons of Sustaining the Project

List your different ideas for sustaining your project in the left column. Then discuss the pros and cons for each method.

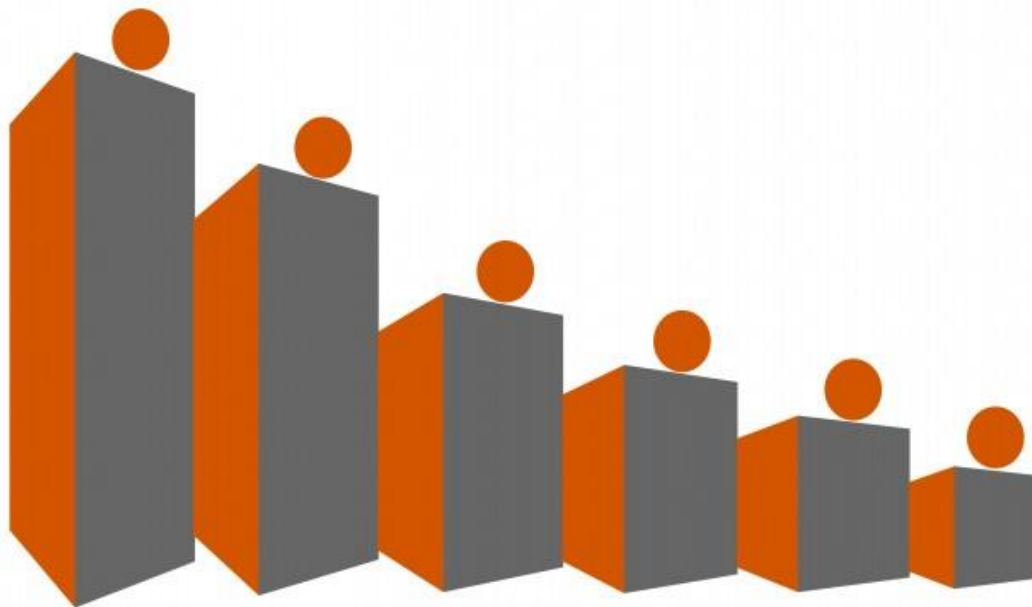
Ways to Sustain the Project	Pros	Cons

Chapter 10: Understanding Results

An important part of the CBPR process is to have the team discuss what the study results mean for the community. Each team member brings their own individual perspective to understanding the results.

Chapter Goals

- Present data analysis strategy and findings to the CBPR team.
- Facilitate understanding of results within the CBPR.
- Discuss the importance of results/findings.



Worksheet 10.1: Understanding Results

The researcher will present the results of the research and you will discuss the following questions.

1. Do you have questions about how the data was analyzed?
2. What part of the results were difficult to understand?
3. What do you think is the most important finding or result?
4. Do these results surprise you in any way? Are they consistent with what you already knew?
5. How do you think these results effect your community now?
6. Are there any other ways that we should look at this data?
7. What questions does this information leave you with?
8. What changes can be made based on these results?
9. How do you suggest that we move forward with the results that we have?

Notes:

Chapter 11: Sharing Results and Taking Action

Sharing results and taking action are important parts of CBPR.

Chapter Goals

- Discuss who to share results with.
- Discuss ways to share the results.
- Explore ways to take action in the community.

Historically, research has been an industry only open to few, usually those working in universities or scientific labs. Researchers are not always experienced in working with the community and may be seen as being arrogant or “better than.” Researchers don’t always know the best way to share results in the community setting or to apply research to real-world situations.

As African-American community members, we must understand that this is where the CBPR team comes in. *“The game is to be sold, not told”* is an attitude that has dominated the African American community for years. This means that information that is hard to come by should not be given away freely. Within this project, we are attempting to break through these attitudes and share this project with as many people as possible.

Beyond just sharing the results of our research, we may also want to take action to improve the community. Action has traditionally been an important part of CBPR. Action can be part of sustainability of the project. .

Worksheet 11.1: Sharing Results and Taking Action

As a team, talk about the discussion questions below to figure out how to share your results and take action.

Discussion Questions

1. Now that you have this information, who would you tell about the work that we have been doing?
2. What methods could we use to tell others about the results of the project? (flyers, posters, reports, etc.)
3. What action would you be willing to take to let others know about our results?
4. Are there people in the community with leadership roles that we could tell about our work?
5. What actions would we want other people to take based on our research results?
6. How could these results improve your community?
7. How could these results improve other communities?
8. What actions are you personally willing to take to change your community?