Inspiring Change

Manual

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

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PREFACE

Welcome to your interactive Inspiring Change manual for community-based participatory research (CBPR)!

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 manual was created to address these health care obstacles by involving 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.

Welcome to Community-Based Participatory Research!

This training and program manual will be used by the CBPR project leadership triad. The manual both guides the training for the leaders and serves as a program manual to engage the CBPR team. The leadership will initiate the project by choosing a research topic, recruiting additional CBPR team members, and facilitating CBPR meetings. The leadership will be responsible for managing all aspects of the project and ensuring that project goals are accomplished on time. We envision that the leaders will include a researcher, a person with serious mental illness, and a community health care provider, who are described in detail below.

Leadership Roles

1) **Researcher**: The researcher brings advice on research methods, data analysis and access to an Institutional Review Board (IRB). The IRB is a group that protects human research participants. For ethical reasons, all research on humans should be approved by an IRB. The researcher should

come from a university or research institute and have experience with managing research projects.

2) **Person with Lived Experience**: The person with lived experience brings personal experience and community knowledge. In this case, this person must have the capacity to learn about research and interact positively with peers in a leadership role. In many instances, this will be the person that the other team members will look to for answers and explanations, regarding the project. An ideal candidate might be someone who is in recovery from mental illness and is doing advocacy or peer support work.

3) **Service Provider**: The provider brings community resources and a professional network. The provider should have the support of his/her agency for participation in the project and should have time and interest to devote to the project.

The research project can be initiated by any of the three above individuals, who will then recruit partners to serve as co-leaders for the project. The leadership triad may already know one another through a local community agency, or may have been introduced to each other through their passion about a certain issue. If the individual members of the leadership team are in different locations, this may create additional challenges and should be addressed before the start of the research project. Consistent communication will remain essential throughout the entire project and the leaders must make a commitment to meet regularly and be fully prepared prior to each CBPR meeting.

Using the Manual and Workbook

The leadership triad should meet as a group during training to complete Chapter 1 of the manual. Chapter 1 helps the leaders to clarify leadership roles, organize the project, plan for meetings and recruit a team of 5 to7 African-Americans with lived experience of mental illness or other community leaders. Chapter 1 is designed to take several sessions for the leadership triad to complete. **It is extremely important to be aware that community-based participatory research projects require a large amount of time to complete. Extra time must be built into the research plan to account for the unexpected.** Also, keep in mind that the leadership will need to recruit the rest of the team before proceeding to Chapter 2 of the manual. Please do not assume that your recruited members are coming into the project with research knowledge even if they have prior CBPR experience. This is the beginning of a new project and should be treated as such.

Chapters 2 through 11 of the manual are used by the leadership to structure CBPR sessions throughout the project and to engage the CBPR team. The workbook that accompanies the manual will be given to all CBPR members and used during CBPR meetings. The manual crosswalks with the workbook. team members should NOT be asked to read and complete the written material outside of CBPR sessions. This material is meant to be interactive! First, spend some time preparing for meetings and thinking about how to best engage the team. Next, be certain to meet once or twice prior to the scheduled meeting to complete the chapter being used and to assign presentation duties. The manual should not be read to the team its' purpose is to guide the leadership in using the workbook with the CBPR team. The workbook activities will help to engage and involve the team at each step in the research process. Present the material, give the team several minutes to complete the activities, then discuss and add decisions to the action plan. Note that leaders are also part of the CBPR team. Leaders should try not to create a feeling of "us" (leaders) versus "them" (CBPR team members). All members are working together towards a common goal.

Checkboxes in the manual indicate instructions for the leaders to use while the team completes the workbook activity. This should be a time used by the leaders, especially the lived experienced leader, to become aware of the individual team members strengths and weaknesses. These observations are to be discussed among the leaders during the debriefing session that will happen after each CBPR meeting. When the workbook instructions require reading, you may wish to have team members take turns reading to help with engagement. You will see references to the "Action Plan" throughout this manual. The Action Plan is the running "to-do" list that the Project Lead will use to keep track of task completion. Each chapter may take more than one session to complete, depending on your meeting schedule, team members and project type. In addition, the manual appendix contains templates and supplemental materials to help the leadership plan and structure their work.

Developing 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 also thank Patient-Centered Outcomes Research Institute (PCORI) for the financial backing for this project.

For the Person with Lived Experience

What Will I Get Out of CBPR?

You can use your CBPR experience as an opportunity for individual and professional growth. Recognition among your peers will become a bright spot in your life. Also, you can meet new people, learn new skills, help others, take on new challenges, get work experience, accomplish something you can be proud of and whatever else motivates you.

What Do I Need to Know?

In CBPR, you are NOT a research participant—you are helping LEAD a research team. You will NOT be the one filling out the survey--- you will be the one CREATING the survey (or whatever other research methods you decide to use). It is important to note that persons with lived experience are smart enough, good enough and confident enough to fill this role effectively. However, if you do not have very much leadership experience, you may want to consider completing a course on leadership and/or presentation skills before taking on this role. You will also need to be willing to ask your fellow leaders for help and support in taking on this role. As a leader on the team, you will be a coworker or colleague to the other team members rather than a client/patient. This can be a difficult role change for some individuals and you will want to think about how this might be for you.

<u>CBPR takes time—think carefully about whether you really have the time needed for this project before you commit.</u>

What Skills Will I Need?

Being the leader of a CBPR project requires special skills and abilities. Here are some qualities that are helpful in a CBPR leader with lived experience:

- Enthusiasm
- Be well-organized
- Be a good communicator
- Have knowledge of the community

- Have rich life experience related to the research topic
- Respect others by listening and being open to other viewpoints
- Dedication and willingness to work hard on a project
- Flexibility

The lived experience leader will be the most accessible among the leadership team. It will be important to create healthy boundaries as well as connect on a more personal level with the other team members. This will require that the person with lived experience be able to complement the team member strengths and weaknesses while completing specific tasks**.**

How Do I Start a CBPR Project?

There is not simply one way to begin a research project. However, the research project starts with a topic that is important to you. Here are some suggested steps to help you move a project forward:

- Sit down, think about your own experiences, and brainstorm ideas. Think about:
  1) What problem or issue do you want to understand more?
  2) What solution can you design to help improve the health of yourself or others?
  3) Can you test an existing program or service to see how well it is working?
- Use a resource center/drop-in center to discuss ideas with other people with lived experience. See if there are others who are interested in helping.
- Speak with a care coordinator or other staff about your idea. Ask them to connect you with others who might be interested in helping with a project.
- Think about how you will "sell" your idea. How will this research help your agency? How will this research help the community?
- Use your agency's resources, other existing groups, or advocacy organizations to recruit other CBPR leaders or team members. For example, some agencies have a group of consumers, called a Consumer Advisory Board (CAB), that meets regularly to discuss the needs of agency consumers.
- Go to the director of your agency or the research department of your agency and discuss your idea. If you have agency support, this will greatly improve the chances of your project's success.
- Ask staff at your agency for help finding a local researcher who can partner with you.
- Develop a proposal and budget for your project. Look through the rest of the manual and use the resources for help with the proposal and budget.
- Ask agencies and/or charitable organizations that have an interest in your research topic for money to carry out the project.

- The first people that you approach might not be interested or may not have the time to take on a project with you. Be persistent and see how the project moves forward.

For the Researcher

What Will I Get Out of CBPR?

As a researcher, you can use the CBPR approach to better understand the community and see how research can be put into action.

What Do I Need to Know?

- As a researcher using CBPR, you are part of a research team. Be mindful this is a different approach to traditional research and you may NOT necessarily be an expert in CBPR. It is important not to take over and impose your ideas on the team; however you will be expected to participate in all aspects of the process.
- Share your research knowledge and gently guide the project to give it scientific credibility. Be an active participant, especially when research methods and ethics are being discussed.
- Be able to appreciate and learn from the knowledge and experience of your team.
- Be prepared to outline and explain research in a thorough yet concise manner. Be prepared to conduct a literature review for the team and do most of the writing-based tasks.
- As a leader on the team, you will be a coworker or colleague to the person with lived experience. This can be a difficult role change and you need to recognize how you can best support the lived experience leader in this transition.
- CBPR takes time—think carefully about whether you really have the time needed for this project before you commit.

What Skills Will I Need?

The researcher on a CBPR project should have advanced training (at least master's level) in qualitative and quantitative research methods. The researcher should have experience managing a research project, including submitting applications for Institutional Review Board approval, collecting data and analyzing results. Here are some personal qualities that are helpful in a CBPR researcher:

- Patience: CBPR can be more time-consuming
- Skilled in conducting literature reviews
- Ability to identify and use strengths of team members
- Willingness to consider different viewpoints
- Ability to communicate in layman's terms
- Flexibility and compromise
- Ability to explain research concepts step by step
- Ability to be present and hands-on at meetings

How Do I Start a CBPR Project?

As a researcher, you may have to develop more connections in the community before you can get started. Consider the following steps:

- Identify a general topic of interest without forming too many specific research ideas.
- Think about your current social network and see whether anyone you know may have lived experience with this topic or can refer you to someone who does.
- Approach people with lived experience to get a sense of common issues and topics from their perspective.
- Think about what a diverse CBPR team would look like in relation to your topic.
- Through your connections, find an agency to partner with on a project.

For the Health Provider

What Will I Get Out of CBPR?

As a provider, this is a chance to facilitate change within your agency and development stronger relationships with the clientele that you serve. Trust, recognition and personal growth are just a few of the benefits CBPR has to offer health service providers.

What Do I Need to Know?

Be caring and considerate, but **take off** your "provider hat." You are there to do research, not to provide services. Other CBPR team members are your colleagues, not your clients**. CBPR requires time and you will need to have some flexibility with your other job duties in order to fully commit to a project**. Think carefully about whether you really have the time needed for this project before you commit.

It will be important for you to have a direct contact with the person in your agency that handles the finances and ultimately makes the final decisions regarding policy. This may be one person but many times it is not. Find out the specifics before you begin the project. As a CBPR leader representing the agency, you will need to know the money issues before you begin the project and be prepared to explain these issues to the other leaders as well as the rest of the team.

As a leader on the team, you will be a coworker or colleague to the person with lived experience. This can be a difficult role change and you need to recognize how you can best support the lived experience leader in this transition.**What Skills Will I Need?**

Being the leader of a CBPR project requires special skills and abilities. Here are some qualities that are helpful in a CBPR health provider:

- Organized
- Ability to communicate importance of project to supervisor and colleagues.
- Task-oriented
- Skilled in time management
- Has knowledge of the community

- Can bring out the strengths of others
- Ability to be present and hands on with project
- Flexible

How Do I Start a CBPR Project?

There is not simply one way to begin a research project. However, the research project starts with a topic that is important to you. Here are some suggested steps to help you move a project forward:

- Think about your own experiences in providing health services, and brainstorm ideas. Think about:

    1) What problem or issue do you want to understand more?
    2) What solution can you design to help improve the health of yourself or others?
    3) Can you test an existing program or service to see how well it is working?
- Think about how you will "sell" your research idea to others (i.e.- what benefits will it bring to the agency?)
- Speak with your supervisor about the feasibility of you devoting time to a project
- Ask your agency whether any funding is available to carry out a project. Work with your research department or grant writer to seek out grants.
- Talk with former professors to locate interested researchers to partner with.
- Recruit people with lived experience, coworkers and researchers who have similar research interests to yours.

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Chapter 1: Getting Started

This chapter provides an introduction to Community-Based Participatory Research (CBPR) for the leadership triad that will guide in developing the leadership structure, recruiting CBPR team members, and preparing for meetings. Research projects will address primary health care needs of an agency's service recipients who are African-Americans with serious mental illness.

This chapter should be completed together by the CBPR leadership.The leadership is comprised of three individuals who will lead the project, one of whom will be a researcher and one of whom will be an African American with serious mental illness. A third leader is a health service provider. Together, the leadership will recruit an additional 5 to 7 African Americans with lived experience who will comprise the full CBPR team. This chapter will guide you through that process.

Once you, as leaders, have completed this chapter, you are prepared to hold the first session with the entire CBPR team that you have recruited. Chapters 2-11 are step-by-step guides for each stage of the research project.

Chapter Goals

- Build leadership's understanding of CBPR.
- Choose a research type and topic.
- Compile preliminary research plan.
- Recruit CBPR members.
- Prepare for meetings.

About Community-Based Participatory Research

As a CBPR leader, we want you to understand the journey on which you are embarking. Take some time to carefully read the definition of CBPR below:

> Community-based participatory research (CBPR) is a **collaborative** approach that involves all partners in the research process. This research format recognizes the **unique strengths** of each partner. 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)

- ☐ Discuss with the other leaders what this definition means to them.
- ☐ On the next page, read the abbreviated examples of CBPR projects that address health disparities for African-Americans.

Example 1

Mental Health Access Project

A group of concerned citizens being treated for mental illness is outraged that funding cuts have forced the closure of a mental health clinic in their predominately African-American neighborhood. They reach out to a local university to help study the social and economic impacts of the closure. Drawing on problems identified by the citizens group, researchers decide to use focus groups, surveys and community mapping to measure the impact of the closure. The citizens group presents the study results to the media and local politicians to highlight the need for mental health services in the neighborhood.

Example 2

Self-Advocacy Training

A case manager feels that his clients need training to advocate for themselves during doctor visits. He recruits a CBPR team to design an advocacy training. The team holds interviews and focus groups with doctors, case managers and clients to identify ways to improve self-advocacy. The team develops a brief self-advocacy training for clients based on their research.

Example 3

Peer Navigator Program

Now, turn to

A university researcher learns about the success of peer navigator programs for cancer patients. Peer navigators are people in recovery from cancer who help patients currently in cancer treatment navigate the health care system. The researcher wonders if this peer navigator model could also be used to improve the health of homeless African-Americans with mental illness in the Chicago's Edgewater-Uptown neighborhood. He writes and receives a federal grant for study using CBPR. He hires a consumer research team, consisting of homeless African-Americans with mental health challenges ("lived experience").

The team is paid to meet regularly with researchers to help plan the project. The group partners with a community organization that hires the peer navigators to provide services. The research staff interview the program participants assigned to work with peer navigators and measure their health in comparison to other homeless African-Americans who did not receive peer navigator services.

- Worksheet 1.1: Opportunities and Challenges of CBPR on page 21). In your first leadership meeting, each leader should have listed opportunities and challenges that might come up with the CBPR approach used in the above examples.
- Each person should also reflect on why they are interested in being part of this project.
- After completing the list, come back together and discuss these opportunities and challenges. If any members of the leadership decide that they are not ready to commit to the project at this time, the remaining members should find another leadership member to recruit.

Worksheet 1.1: Opportunities and Challenges of CBPR

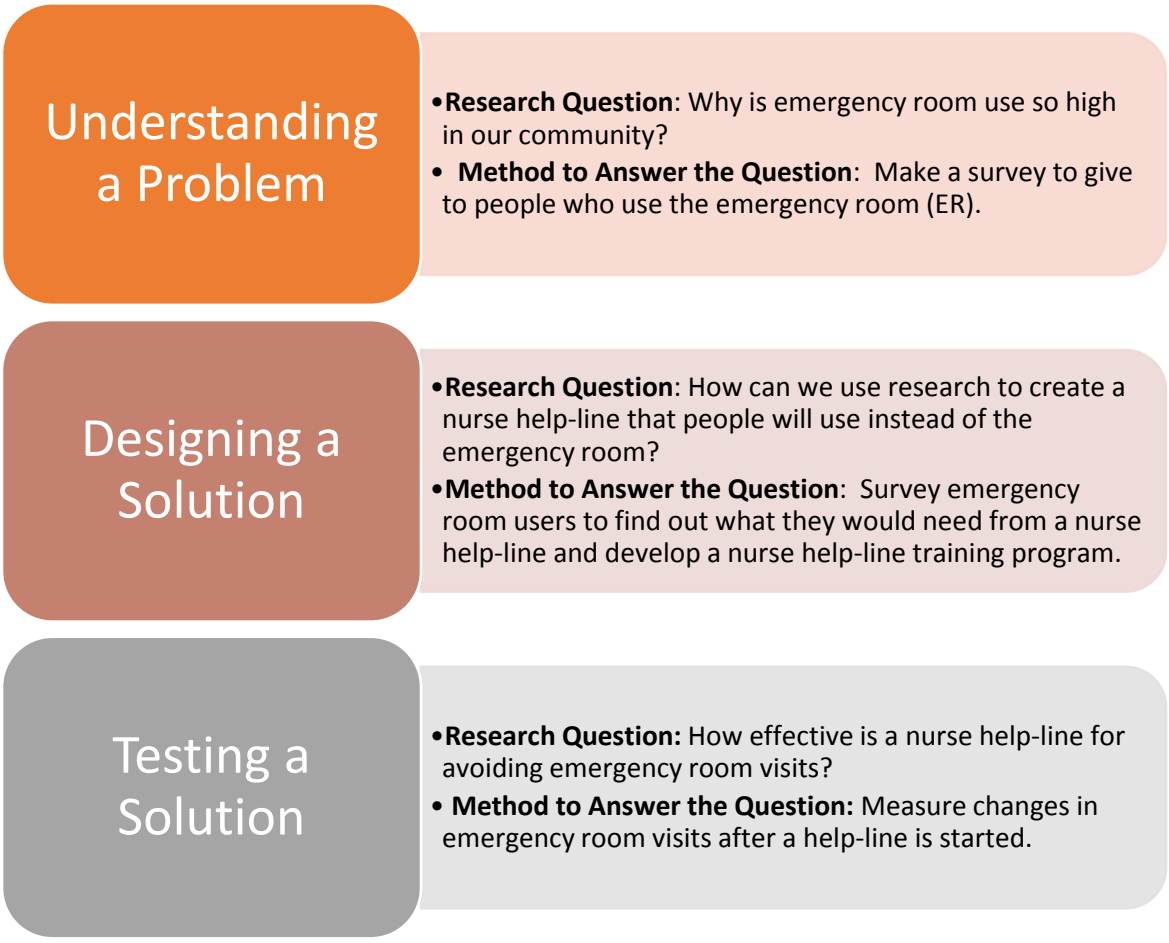
Instructions: Think about some opportunities and challenges there might be during a CBPR project. List these in the chart below.

Opportunities	Challenges
e.g- It will bring attention to an issue that you feel is important	e.g.- It is a big time committment
.	.
.	.
.	.
.	.
.	

Why do I want to be involved in CBPR?

Developing a Topic

At this point, you may already have a specific topic in mind *or* may be feeling overwhelmed with ideas. Either way, you should discuss your options in a systematic way. You do not need every detail of your plan at this point; you will still need input from your larger CBPR team once you've recruited them. Now you will begin structuring the project so you know what to look for in your CBPR team. For example, if your project focuses on dental care access, you will want team members who are interested in this topic and who have particular experiences or expertise in dental care. We recommend that you limit your research to one of the three types in the figure below. This figure gives an example of each research type: Understanding a Problem, Designing a Solution and Testing a Solution.



- ☐ As a group, use Worksheet 1.2: Generating Topic Ideas starting on page 23 to list your ideas. (We have also included a list of topic ideas, located in the appendix on page 99, to give you examples of topics.)

Worksheet 1.2: Generating Topic Ideas, Part 1

Use the questions provided for each research type to brainstorm ideas. At this point, avoid criticizing any ideas or thinking too much about practicality.

Understanding a Problem

1. As an African-American or provider for African-Americans with serious mental illness, what frustrates you about the health care system?
2. How do you think attitudes or stigma present barriers to health care for African-Americans with serious mental illness?
3. What are the most pressing issues in the African-American community that might affect physical and mental health treatment?
4. What keeps African-Americans with serious mental illness from getting treatment?
5. What keeps African-Americans with serious mental illness from staying in treatment or following treatment recommendations?

Write your ideas here:

Worksheet 1.2: Generating Topic Ideas, Part 2

Designing a Solution

1. What special needs do African Americans with serious mental illness have in your community that could be addressed through an intervention?
2. What role might spiritual or religious communities play in health care for African Americans with serious mental illness?
3. What ideas do you have for improving health care for African Americans with serious mental illness?
4. How can you make integrated care work better for African Americans with serious mental illness?
5. How do you engage more African-Americans with serious mental illness in health services?
6. How can treatment providers be more culturally competent for African-Americans with serious mental illness?
7. What are better ways of doing outreach to African Americans with serious mental illness who are not currently involved in the health care system?

Write your ideas here:

Worksheet 1.2: Generating Topic Ideas, Part 3

Testing a Solution

Think about treatments that you've provided or that you have taken part in.

1. Are there any you would want to test to see how well they work?
2. What community programs to improve health care (outreach, education, therapies, etc.) could be tested to see how well they are working?
3. What are counseling interventions that might be tested?
4. How would you know that a program is working well?
5. What kinds of things would you want to measure?

Write your ideas here:

Narrowing the Topic

If your topic is too narrow, you may have trouble finding enough participants (e.g. health care access for anorexic African-American mothers with children under age 5).

However, if your topic is too broad, you won't be able to complete it (e.g. health care satisfaction of African-Americans with serious mental illness in the U.S.)

- ☐ Complete Worksheet 1.3: Narrowing the Topic on page 27 to decide whether you need to further define/narrow your top three topic ideas.

Worksheet 1.3: Narrowing the Topic

List the three topic ideas from the previous activity that you, as leaders, feel most passionate about.

Topics:

1.

2.

3.

Think about each of these topics and use the questions below to help narrow the scope.

1. Focus on a specific mental illness. What different types of mental illness impact the African-American community?

2. Focus on a specific physical illness. What chronic physical health problems do African-Americans with serious mental illness often face? (e.g.- diabetes)

3. Focus on a specific age group. What age groups are possible targets of the research?

4. Focus on a specific neighborhood. What neighborhoods or areas of the city might you target?

5. What are other special populations that you might focus on? (parents, couples, veterans, homeless, people with substance abuse, LGBTQ, people living in nursing homes, etc.)

Selecting a Topic

At this point, you will have three well-developed topic ideas.

- ☐ Use Worksheet 1.4: Selecting a Topic on page 29 to evaluate these ideas and make a final decision on a topic.

Worksheet 1.4: Selecting a Topic

Complete the following table for your top choices and discuss your answers. Fill in your final choice at the bottom of the sheet.

	Choice 1 _____	**Choice 2** _____	**Choice 3** _____
What resources do you have for this project?			
What challenges do you foresee if you chose this project?			
How familiar are you with this topic?			
Why is this project important to your community?			
How likely is it that this project could be sustained?			
How realistic/ feasible is this project?			

Our topic choice is: _____

Evaluating Your Resources

Here we present a guide to evaluate your resources. If you need to seek funding, please see additional resources beginning on page 119.

For community-based projects, it is wise to strategically evaluate your available community resources. We offer the following acronym, CNP to guide your efforts.

Collaborate with people and organizations. Others in the community may have a similar project or mission. An existing Consumer Advisory Board may help with your research project as one part of their duties. Think about individuals within your organizations, including upper management, who can be champions for your project, or who can provide administrative support (e.g. managing finances).

Network with others. Tell people you know about the project and ask them to share resources.

Partner with community organizations. Build strong relationships in which both parties benefit. The organization may provide you with a meeting room and the research will help them improve their services for African-Americans with serious mental illness. This may be an opportunity to work with an agency to write a grant together. The appendix provides additional information on working with community partners.

- ☐ With these resources in mind, complete Worksheet 1.5: Resource Analysis on page 31 together and discuss.

Worksheet 1.5: Resource Analysis

Discuss ways that you can collaborate, network or partner with other organizations and write them here.

NEEDED RESOURCES	**AVAILABLE RESOURCES**
OPPORTUNITIES FOR RESOURCES	**CHALLENGES**

Organizing the Project

This section provides guidance for organizing the team and project in preparation for the first CBPR team meeting.

Timeline

Now that you have developed a topic, you will work on a preliminary timeline. After meeting with the whole CBPR team, you will introduce the timeline to the rest of the team and make revisions as needed.

Tips

Be very specific in the timeline.

Build in some extra time for unforeseen delays!

At each meeting, present the timeline to the team to update the accomplishments and make sure that the project stays on track.

If the project is not going as planned, the leaders need to communicate with each other to decide if major changes to the timeline and project scope need to be made. **In Chapter 3, you will talk with your team about group decision-making. However, to move the project along, the leaders will need to make some of the decisions first, and then get feedback from the group.**

- ☐ Use Worksheet 1.6: Timeline on page 33 to plan project milestones, changing the dates as necessary

Worksheet 1.6: Timeline

Task	Start Date	Completion Date
Example: Recruitment	*Feb. 1*	*March 1*
Chapter 1		
Recruit Team		
Literature Search		
Chapter 2		
Chapter 3		
Chapter 4/5/6		
Chapter 7		
IRB Application		
Data Collection		
Chapter 8		
Chapter 9		
Chapter 10		
Chapter 11		
Others:		
Final Report		

Responsibilities

Now you will decide on specific responsibilities for each leader, keeping in mind, that one person should be designated as Project Lead. The role of the Project Lead

is to keep the project on time and on budget. The Project Lead can be the researcher, provider, or person with lived experience; however, he or she will need to be detail oriented, well organized, have time management skills and have enough time to devote to this important role. **The Project Lead is the one responsible for making sure the project gets done and for delegating tasks as needed**.

Two of the leaders will co-facilitate the group meetings; one of the co-facilitators should be the person with lived experience. Please note that co-facilitating is a very difficult endeavor. Co-facilitators will need to become comfortable working together and will need to decide how to divide the responsibilities. For example, the co-facilitators might take turns leading sessions or each take a part of the agenda to lead**. Co-facilitators will meet in advance of the group to plan and debrief together afterwards so they can maintain the same vision for the group.**

- ☐ Complete the chart below to decide responsibilities and payment on the project.

	Primary Responsibilities	Expected Hours	Payment Amount	Payment Method
Researcher				
Lived Experience Leader				
Health Provider				

The Project Lead is: _____

Planning for Meetings

Most groups decide to meet weekly during project start-up and then less often (biweekly or monthly) as the project progresses. Remember to consider possible travel barriers and scheduling conflicts when you plan times and locations. You may need to change time or location later based on CBPR member schedules and preferences. You must also decide if you will be able to provide any money or compensation for CBPR members and should inform potential group members of the meeting plan during recruitment. **Be transparent about payment and work expectations. Make sure all members, including leaders, agree on the number of expected hours, payment amount, and method of payment in advance.** This should be provided in writing at the beginning of the project.

The leadership will decide in advance who will facilitate each session. The assigned facilitator or co-facilitator will review each session to ensure that he or she is prepared. **Being organized and prepared is the best way to build the trust of your team.**

The leadership team should arrive early to set up the room, review the agenda, greet the team members, pass out supplies and take attendance. At the first meeting, provide team members with a folder or binder to store project paperwork.

One of group leaders should begin each week's session by reading the minutes of the previous session and asking for CBPR approval. This allows a review of what happened last week and makes a transition into the current week's objective. Get to know your team and go at their pace. Do not overwhelm them with too much information at once, but make sure that you are transparent and are involving all individuals in the process. Once the minutes are approved, the group facilitators should move immediately into the prepared agenda. Be aware of how the group is responding to each session and change up your style and activities as needed. **The leadership triad should meet after each group meeting to debrief and outline the agenda for the next meeting.**

- ☐ Fill out Worksheet 1.7: Meeting Plan on page 36 to develop your meeting plan.
- ☐ See the appendix for examples of agendas and minutes on page 81.

If you will compensate the CBPR team members or need help with budgeting, see on page 125 for guidance.

Worksheet 1.7: Meeting Plan

Meeting Schedule

Our group will meet: _____
Best days of the week: _____
Best times of day: _____

Meeting Location: _____

Supply Checklist

Check which supplies you will need from below:

- Folders/binders for team
- Computer
- Coffee
- Sugar
- Stirrers
- Water
- Utensils
- Food
- Notepads
- Others_____
- Weekly handout/agendas
- Projector
- Cups
- Creamer
- Juice
- Plates
- Napkins
- Pens
- Whiteboard markers/chalk
- Others_____

Division of Responsibilities

Fill in person who will complete each task, or enter N/A if not applicable.

Task	Person Responsible
Reserve meeting space	
Reminder calls	
Set-up	
Clean-up	
Bring supplies (pens, paper, etc.)	
Print agendas/handouts	
Bring food/drinks	
Take meeting minutes	
Manage payments	

Literature Review

The leadership needs to become knowledgeable about past research on the chosen topic. In preparation for the first CBPR meeting, the researcher should complete a review of the literature on the chosen topic and prepare a brief summary for the rest of the team. It will be important that the researcher does this literature review in addition to what the other leaders may have already done. This should be a brief, condensed version of a literature review (1-2 pages) that summarizes past research on the topic, including the problem, past attempts at solutions, and identification of gaps and/or needs. The review should be in understandable language and may be presented in bullet points and/or PowerPoint presentation.

There is a template for literature review on page 87.

- ☐ Add dates of completion for the literature review to the Action Plan on page 96.

Project Information Sheet

Based on the decisions made in Chapter 1, the leadership will create a project information sheet. This document is given to each CBPR member at the first meeting and provides an overview of the project. A project information sheet template is provided on page 88.

- ☐ Decide who will create the project information sheet and add this item to the Action Plan on page 96.

Recruiting Your CBPR Team

The goal of CBPR is to include the community in research-- and in this case your recruitment will target primarily African-Americans with serious mental illness. However, it may be necessary for your project to include other individuals as well. For example, if you want to do a project with a faith-based community, it may help to have a clergy member on your team. You will also need to think about group size. If your group is too large, it will be more difficult to make decisions, but if your group is too small, you may be missing some perspectives. We recommend that the CBPR team includes 6 to 10 individuals (including leaders). You'll also want to think about the time commitment that you will be asking of members and how you will handle replacing people who may leave the group.

- ☐ Now turn to on page 38 and complete the Worksheet 1.8: Recruitment.

Worksheet 1.8: Recruitment

Team Members

Check those that you will include in your group and write the number of individuals that you will recruit in the space to the right.

- ❑ Researcher _____
- ❑ Lived Experience Service Recipients_____
- ❑ Service Provider_____
- ❑ Family Member_____
- ❑ Clergy_____
- ❑ Organizational leader_____
- ❑ Other (specify)_____

Recruitment Methods

Here are some ways you can recruit team members. Check all that you plan to use:

- ❑ flyers, list places to distribute_____
- ❑ email/listservs: specify names_____
- ❑ ask key people for recommended members, specify names_____
- ❑ presentation at organizational meetings, specify names_____
- ❑ use currently existing group (ex-Consumer Advisory Board at health agency)
- ❑ social media: list media (e.g. Facebook) _____
- ❑ other (specify)_____

Time Commitment

We will ask team members to commit _____ hours per week for _____ months.

Replacing Team Members

We will replace team members:

- ☐ Whenever a team leader leaves
- ☐ Only if team member leaves within _____ weeks/months of project start
- ☐ Never
- ☐ Other

Other Recruitment Considerations

List any other ideas here:_____

Selecting Your CBPR Team

Once you have a pool of potential CBPR members, you will go through a selection process. You should conduct this process in a professional and transparent way, so that you can find the best team members. **Resist the temptation to accept the first people who are interested or to only consider people that you already know. The goal is to recruit a diverse team that can understand and solve community problems.** Ideal candidates should be enthusiastic, willing to commit time/effort and capable of working in a group setting. However, be careful not to exclude people merely because of their substance use, criminal history or mental illness symptoms. In CBPR, these experiences are viewed as assets to the team. These diverse perspectives can help improve the research.

- ☐ Turn to on page 40 and complete the Worksheet 1.9: Selecting Your CBPR Team.

Worksheet 1.9: Selecting Your CBPR Team

The answers you choose will guide your interview questions and/or application process.

1. What are we looking for in a candidate? Check all that apply:
   - ❑ commitment level
   - ❑ enthusiasm
   - ❑ can work well with others
   - ❑ ability to understand the project
   - ❑ other_____
   - ❑ other_____

2. What are we looking for in terms of group diversity? Check all that apply:
   - ❑ ethnicity
   - ❑ age
   - ❑ physical health
   - ❑ mental health diagnosis
   - ❑ sexual orientation
   - ❑ education
   - ❑ work experience
   - ❑ others_____
   - ❑ other _____
   - ❑ other_____

3. What process do we go through to select candidates?
   - ❑ phone screening/phone interview
   - ❑ recommendation letters
   - ❑ reference checks
   - ❑ written application
   - ❑ in-person interview
   - ❑ other_____
   - ❑ other_____

List tasks from above on the Action Plan on page 96. For example, if you decided to do an in-person interview, list that on the plan and decide who will conduct the interviews.

Engaging the Team

You need your team to stay interested and invested in the project for the long haul. Thus, before you begin, you need to think about how you will accomplish engagement. The workbook that goes with this manual is one tool to help you with engagement. As leaders, you can discuss additional creative methods of engagement that draw on the individual strengths of each leader. For example, if one of the leaders is a more dynamic speaker, he/she should have a larger role in leading the group sessions. The goal of engagement is to keep the team excited, to let the team know that their input is valued and to build trust in the leadership. Here are some ways you might engage the team:

- Highlight individual member contributions in the group.
- Review group accomplishments every month.
- Spend time summarizing the previous session and check that all team members understand.
- Review group rules periodically.
- Provide drinks and snacks for meetings.
- Limit the length of any one activity to 45 minutes or less.
- Individually call out group members and ask for their opinions on research topics.
- Allow members formal and informal opportunities to give feedback to the leadership.
- Have periodic (weekly or monthly) personal check-ins to build rapport among team members.
- Honor birthdays by giving cards or bringing treats.
- Depending on the project, the CBPR team can be involved in collecting data, analyzing data and understanding the results. See the appendix on on page 108 for further engagement ideas to use during data collection.

☐ Use Worksheet 1.10: Engaging Your CBPR Team on page 42 to plan how you will engage your team.

Worksheet 1.10: Engaging Your CBPR Team

Engagement means keeping all CBPR team members involved and interested in the project. List the ways that you, as project leaders, plan to engage your team.

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

11.

12.

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17.

18.

19.

20.

Providing Reasonable Accommodations

Accommodations are special supports or allowances that are provided for CBPR team members to help them participate and be included despite barriers that they may experience. 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.). Accommodations should be reasonable and should be applied on a case-by-case basis to allow for maximum participation of CBPR team members.

- ☐ Complete Worksheet 1.11: Providing Reasonable Accommodations on page 44 to begin thinking about accommodations that might be needed. A list of possible accommodations for people with serious mental illness is provided on page 104 to help you generate ideas. You will also talk more about accommodations with the CBPR team in Chapter 3.

Worksheet 1.11: Providing Reasonable Accommodations

Accommodations are special supports that are provided for CBPR members to help them participate and be included despite barriers they may have. List the accommodations that you, as project leaders, might provide to CBPR team members.

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

Working Together

At one of the first CBPR team meetings, you will complete Chapter 3: Working Together. In Chapter 3, you will meet with your team to develop group rules, discuss group decision-making and cover related topics on group communication in detail. Leaders will benefit from thinking about two possible issues before covering them more fully in Chapter 3: dual relationships and power dynamics.

Dual relationships occur when members of the CBPR team have a personal or professional relationship outside of the group.

- ☐ Discuss with other leaders how dual relationships might impact work of the team.

Power dynamics explains how power is shared in the group. Some members of the group may come in with more "social power" because they have education, knowledge, or more financial resources. A goal of CBPR is to have a more equal share of power.

- ☐ Discuss how power might be shared among members of your group.

Using the Manual and Workbook: Final Notes

The rest of this manual will be used along with the Inspiring Change workbook. Each CBPR team member will receive a copy of the workbook. The leaders will use this manual to guide group activities in the workbook throughout the course of the project. Major topics covered in CBPR sessions will be:

Chapter 2: Introduction to CBPR

Chapter 3: Working Together

Chapters 4-6: Understanding a Problem, Testing a Solution, Designing a Solution

Chapter 7: Research Ethics

Chapter 8: Collecting Data

Chapter 9: Sustainability

Chapter 10: Understanding Results

Chapter 11: Sharing Results and Taking Action

Attention Leaders:

The subsequent chapters will be completed with the entire CBPR team. Recruit your team and prepare materials before proceeding.

Chapter 2: Introduction to Community Based Participatory Research

This chapter serves as a guide for the first meeting of the CBPR team, which will be facilitated by the project leaders. Schedule a meeting for the leaders only prior to this meeting and complete the chapter assignments. During the leadership meeting discuss the chapter goals and assign specific activities for each leader to facilitate.

Chapter Goals

- Explain CBPR definition and principles.
- Orient CBPR team to basic research concepts.
- Build understanding of specific research topic.
- Build rapport within the team.

Introduction

- ☐ Introduce the term "Community-based participatory research" (CBPR) as a new, innovative way of doing research (try to build excitement for the project).
- ☐ Each member of the leadership introduces him/herself and talks for 2-3 minutes about his/her experiences and why they are interested in this project.
- ☐ The leadership provides the team members with the project information sheet that was created in Chapter 1. Together, read through the information on the sheet.
- ☐ Ask if team members have questions.
- ☐ Stress that although the leadership has a chosen topic, the CBPR team is needed to help further develop the project.

CBPR Definition

- ☐ Ask group members to find the Worksheet 2.1: Introduction to CBPR in their workbook.
- ☐ Read the definition aloud and explain the bold/underlined words in laymen's terms in context of their project. For example, for the word "collaborative" they would say something like "Researchers and community members will be working together on this project."

Ice Breaker Activity

- ☐ Ask group to break into partners. The partners will ask each other the following questions.
  - Name and agency
  - Why are you interested in the project?
  - What strengths or skills do you bring to the project?
- ☐ Ask members to convene back to the large group, introduce their partner and tell about their partner to the larger group.

Community-Based Participatory Research Definition and Principles

- ☐ Ask team members to take turns reading each principle on Worksheet 2.2: CBPR Principles.
- ☐ Use the questions in the right-hand column of the worksheet to discuss how each principle can apply to their own project.

The Research Process

- ☐ Ask team to turn to Worksheet 2.3: Research Process Worksheet.
- ☐ Introduce the steps of research and have members read the definitions and examples.
- ☐ Tell the team that later you will have meetings that cover each of these stages in more detail, but right now you want to give them an overview of the process.
- ☐ Go back through each stage on Worksheet 2.3 and ask team members to give examples of what you might do for each stage of your project. Remember, the purpose here is for the group to understand the research process, not to develop your research plan, so do not spend too much time discussing specific methods, actions, etc.

Roles & Responsibilities

- ☐ Introduce roles and responsibilities of project in context of your project.
- ☐ Read each description and identify who will serve each role on the project.

- ☐ Ask CBPR team if they have any questions about these roles and responsibilities.

Chapter 3: Working Together

Schedule a meeting for the leadership team only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership and should include the entire CBPR team using the workbook. The leaders should already be familiar with the workbook activities and should be prepared to facilitate specific engagement activities.

Chapter Goals

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

Group Rules

- ☐ Tell the team that although this is a goal-oriented group rather than group therapy, rules for communication must be developed.
- ☐ Ask the team: Why is it important to have effective communication in a group? (E.g. so everyone gets a turn to speak, so everyone feels respected, etc.).
- ☐ Encourage members to contribute answers, write on whiteboard/chalkboard and discuss.
- ☐ Ask group to brainstorm rules that they would like to include and have one member take notes.
- ☐ Tell group that leaders will type the list and bring it to the next group meeting for comments and approval. (See on page 102 for an example of group rules).

Once the group rules have been established and agreed upon the leaders should present the rules at the beginning of every other month. The leaders should emphasize the rules that team members have been violating and recite the purpose of the team and the importance of specific guidelines.

Group Decision-Making

- ☐ Ask members to turn to Worksheet 3.1: Group Decision-Making in the workbook. Read descriptions for three types of decision-making options.

- Tell members that all three of these types of decision-making can be used in your group, depending on what kind of decision that you will be making.
- Ask team members to individually write down pros and cons of each type of decision on their worksheets.
- Come back as a group and discuss pros and cons that people identified.
- Tell team that the leaders will do their best to guide the group into the proper decision making option, but team members can call for a different option when they feel it's appropriate.
- Ask team to refer to Worksheet 3.2: Working Together.
- Take turns reading each section aloud.
- Use the discussion questions at the end of each section (*in italics*) to guide your conversation with the CBPR.
- Take notes on ideas generated during the discussion and incorporate into the meeting minutes.

Note:

If your chosen research type is "Understanding a Problem" the next chapter you will complete will be Chapter 4. You will skip Chapters 5 and 6 because these chapters do not address your chosen research type.

If your chosen research type is "Designing a Solution" the next chapter you will complete will be Chapter 5. You will skip Chapters 4 and 6 because these chapters do not address your chosen research type.

If your chosen research type is "Testing a Solution" the next chapter you will complete will be Chapter 6. You will skip Chapters 4 and 5 because these chapters do not address your chosen research type.

Chapter 4: Understanding a Problem

Schedule a meeting for the leadership triad only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership and should include the entire CBPR team. Only complete this chapter if your research topic is about "Understanding a Problem." If your topic is about "Designing a Solution" or "Testing a Solution", go to Chapters 5 or 6 respectively. Note the additional resources for surveys and focus groups are located in the appendix.

Chapter Goals

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

This chapter addresses research that is used to understand a problem within a specific community. Although your group already has an idea for your project, now you should further develop your idea and add in specific details. It is recommended that the researcher lead the activities in this chapter.

- ☐ Ask the team to turn to Chapter 4: Understanding a Problem in the workbook.
- ☐ Read the research type descriptions from the handout.
- ☐ Ask team if they understand the differences and ask them to give examples of research that seeks to understand a problem.
- ☐ Explain that your group leadership has decided to focus on "Understanding the Problem" and remind the group of the chosen research topic.
- ☐ Team members can write the project topic at the bottom of Chapter 4 introduction in the space provided.
- ☐ Ask someone to read the example entitled "Project Example for Understanding a Problem.
- ☐ Ask the following discussion questions aloud to the CBPR team to check for understanding.

    - 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?

Researcher Presentation

This presentation **should be done by the researcher on the CBPR team. This presentation should be concise, but interactive.**

- ☐ Present the team with a review of the current literature on the problem (completed by the researcher in Chapter 1). Answer any questions that team members may have.

Topic Discussion

- ☐ Tell the team that although the leadership has chosen a topic, you would like feedback from the team about the topic.
- ☐ Remind the team that the focus of the project is to improve health care for African Americans with serious mental illness
- ☐ Remind the team about the specific problem that your team has chosen and write it down for all to see:_____ (ex- What are the barriers to African-Americans with serious mental illness getting dental care?)
- ☐ Ask the team:

1. What are your personal experiences with _____ (insert the problem)? In other words, how has this problem impacted you, your neighbors, your family members, your community, etc.?
2. What would you be most interested in learning about this problem?
3. Who in our community knows the most about this problem?
4. What are some challenges we might have as we are trying to understanding this problem?
5. What resources do you have to research this problem? (think about agency partners, neighborhood contacts, etc.)
6. Is there anything else you might change about the topic/research question?

- Take notes on the responses and make changes to the topic/ research question based on the discussion.
- Leaders should feel assured at this point that everyone is on the same page as to what the goals of the CBPR team will be. If the leaders do not feel confident that the CBPR has a basic understanding more time should be given to understand.

Research Methods for Understanding a Problem

- Ask team members to turn to workbook page titled Research Methods for Understanding a Problem.
- The researcher will present each research method to the CBPR team.
- Encourage the team to be open to different research methods.
- Discuss each and check for understanding from the group.

Step by Step Process to Choose Research Methods

- Ask the team to turn to Worksheet 4.1: Choosing a Research Method to Understand a Problem.
- Ask team to form small groups.
- Ask team to think about your specific project and fill in the benefits and risks of each research method. You might need to do the first one as an example.
- Then come back together as a group and discuss.
- Lastly, the entire CBPR team will make a decision on whether or not to use the research method. Make sure everyone understands that more than one method may be used.

Leadership Follow-up

- Project Lead should write any tasks that need to be accomplished on the Action Plan on page 96.
- Researcher should incorporate any changes made during this chapter into the Research Plan on page 89.
- The researcher should draft a consent form for the project. A consent guideline (on page 91) and sample consent form (on page 106) are provided in the appendix.

Chapter 5: Designing a Solution

Schedule a meeting for the leadership team only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership and should include the entire CBPR team. Only complete this chapter if your research topic is about "Designing a Solution." If your topic is about Understanding a Problem or Testing a Solution, go to Chapters 4 or 6. Note the additional resources for surveys and focus groups are located in the appendix.

Chapter Goals

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

Introduction to Designing a Solution

- ☐ Ask the team to find Chapter 5: Designing a Solution in the workbook.
- ☐ Read the description of each research type.
- ☐ Ask team if they understand the differences.
- ☐ Remind the team that the focus of the project is to improve health care for African Americans with serious mental illness.
- ☐ Remind the team of your chosen solution/ project idea_____ (ex- design a pamphlet for case managers that gives information about dental care) and ask them to write it in the space provided.
- ☐ Tell the team that you will only be designing the solution and pilot testing the solution. Explain that pilot testing means a small, short test of the solution to see if it can be done and identify any challenges that weren't expected or improvements that need to be made before testing it with a larger group of people.

Researcher Presentation

This presentation **should be done by the researcher on the CBPR team. This presentation should be concise, but interactive.**

- ☐ Present the group with a brief review of the current literature on the problem (completed by the researcher in Chapter 1). Keep as interactive as possible and answer any questions that group members have.

Group Discussion

- ☐ Tell the group that now they've heard about the research literature, now you'd like to hear their perspective.
- ☐ Use the following questions to guide a discussion. (Note: Leadership should type up a summary of this discussion and bring to the next group session)
  - What is your definition of _____ (insert the problem)?
  - What are your personal experiences with _____ (insert the problem)? In other words, how has this problem impacted you, your neighbors, your family members, your community, etc.?
  - Is there any other information that we need to find out about the problem before we move to the solution? If yes, how can we find out more information?
  - What do you think about the (insert proposed solution)?

Designing a Solution Activity

- ☐ Ask the group members to turn to Worksheet 5.1: Designing a Solution.
- ☐ Discuss the details of the solution/projects and come to a group consensus about each item.
- ☐ One member of the leadership should be designated as scribe to record all information and should bring to the group for approval the following week.

Analyzing the Project

- ☐ Ask the team to turn to turn to Worksheet 5.2: Strengths and Challenges. Tell the group that all research projects will have strengths and challenges. This activity is designed to think more about strengths and challenges for each stage of the project.
- ☐ Have team members fill out the worksheet in small groups and then come back to the larger group to discuss.

Leadership Follow-Up

- Project Lead should write any tasks that need to be accomplished on the Action Plan on page 96.
- Researcher should incorporate any changes made during this chapter into the Research Plan on page 89.
- The researcher should draft a consent form for the project. A consent guideline on page 91 and sample consent form on page 106 are provided in the appendix.

Chapter 6: Testing a Solution

Schedule a meeting for the leadership triad only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership and should include the entire CBPR team. Only complete this chapter if your research topic is about "Testing a Solution." If your topic is about Understanding a Problem or Designing a Solution, go to Chapters 4 or 5 respectively. Note the additional resources for surveys and focus groups are located in the appendix.

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.

At this point, your team already knows what solution/intervention you want to test. In this chapter, you will further develop your ideas and add in specific details. Before beginning this chapter, you should have:

- ☐ Selected the community agency that you will partner with.
- ☐ Met with the leadership of your community partner agency.
- ☐ Obtained formal approval from the agency to test the solution/intervention that you have chosen.
- ☐ A clear and detailed description of the solution/ intervention (from the partner agency) to present to the CBPR team.
- ☐ If possible, participate in the chosen intervention with the CBPR team.

Once you have all of the above complete, you, as leaders, are ready to present this chapter to the CBPR team.

Introduction

- ☐ Give CBPR team a verbal and written description of the solution/intervention that you will be testing.
- ☐ Allow team to ask question as needed and make sure that everyone on the team thoroughly understands the intervention.

- Ask the team turn to Chapter 6: Testing a Solution in the workbook.
- Read the description of each research type.
- Ask team if they understand the differences.
- Explain that your group leadership has decided to focus on "Testing a Solution."
- Explain to the group in "Testing a Solution" you will be finding out how well the solution works, if there are people it works better for and/or how you can improve the solution.
- Explain that as a researcher, you are on the outside, looking in on what the community agency is doing. You are using science to find out if something works. The agency makes decisions about the intervention, while your team makes decisions about the research. Sometimes the needs of the agency will clash with the needs of the agency. The CBPR team focuses on the research and scientifically testing, while the agency makes decisions about services to provide.

Identifying Outcomes

- Tell the team that you now need to figure out **how** we will know if the intervention is working. In other words, what do we want to measure or test? What is the outcome?
- Ask participants to divide into small groups and complete Worksheet 6.1: Identifying Outcomes worksheet. Write the solution/intervention at the top. Brainstorm answers to the following questions
- Come back to the group, discuss answers and prioritize which of these outcomes you would want to test.

Research Methods

- Ask team members to find Research Methods for Testing a Solution sheet from the workbook.
- Read the material as a group.
- Check for understanding by asking team members to give examples of each type of research method as you go.
- Encourage the team to be open to different research methods.

- Ask team to turn to Worksheet 6.2: Choosing a Research Method to Test a Solution.
- As a group, discuss each research method in relation to your project. Use your list of outcomes and make sure that outcomes are listed under the "What does it test?" column.
- After you have discussed each method, talk about which ones you will use. Make sure team members understand that you can use more than one of these methods, but that you will not have time or resources to do all of them.

Making a Plan

- Ask team to turn to Worksheet 6.3: What Do We Need?
- In small groups, ask team members to list each research method you have chosen on the left side. Then small groups will complete the steps needed for each research method.
- Come back to the larger group and discuss (have leader take notes).

Leadership Follow-up

- The leadership should meet with the partner agency to go over the methods and timeline.
- The leadership should get approval and sign written contract to perform the research.
- Project Lead should write any tasks that need to be accomplished on the Action Plan on page 96.
- Researcher should incorporate any changes made during this chapter into the Research Plan on page 89.
- The researcher should draft a consent form for the project. A consent guideline on page 91) and sample consent form on page 106) are provided in the appendix.

Chapter 7: Research Ethics

Schedule a meeting for the leadership team only to discuss the chapter goals and complete the chapter assignments. Each member of the team who will be in contact with research participants or have access to data should complete any additional trainings required by the Institutional Review Board (IRB). This presentation **should be done by the researcher on the CBPR team. This presentation should be concise, but interactive.** The researcher should be familiar with research ethics in the social sciences.

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.

Introduction to Ethical Principles

- ☐ Ask CBPR team to turn to Chapter 7: Research Ethics in the workbook.
- ☐ Introduce the topic of research ethics and tell the team that ethics protects research participants from being harmed by research.
- ☐ Read the ethics definition under the title "What is Research Ethics?"
- ☐ Ask team to think of ethical problems in research and discuss these as a group.
- ☐ Read the descriptions of Nazi experiments and Tuskegee Syphilis study on the following page.
- ☐ Tell members that after these experiments were done, laws were passed to protect research participants.
- ☐ Read the paragraph about IRBs aloud. Tell members that their project will have an IRB and explain how the IRB process will work for their project.
- ☐ Ask team members to look at the next page titled called "Three Ethical Principles" in their workbook.
- ☐ Read each of the principles aloud.

Beneficence

- Read the definition of beneficence from the workbook. One member reads the case study (part 1) aloud.
- Read each component of beneficence in Worksheet 7.1: Beneficence and discuss how it relates to the case study. Ex- risk of heart disease has to be weighed against protection from suicide.
- Members write in examples of violations.

Respect for Persons

- Read case study (part 2) aloud.
- Read each component in Worksheet 7.2: Respect for Persons and discuss how it relates to the case study.
- Members write examples of violations on the worksheet.

Justice

- Read case study (part 3) aloud.
- Read each component in Worksheet 7.3: Justice and discuss how it relates to the case study.
- Members write examples of violations on the worksheet.

Application of Ethics to Current Project

- Ask group members to turn to Worksheet 7.4 Project Risk and Benefits in the workbook.
- Ask team members to think about risks and benefits of their research project for the participants and for the community.
- The group should decide whether the expected benefits outweigh the risks. Decide whether to revise the project based on the risks versus benefits.

Informed Consent Review

The CBPR team will review the consent document for their research project to make sure there are no violations of ethical principles and that consent document is understandable.

- Present a draft of the informed consent document(s) for your project.
- Ask CBPR team to find Worksheet 7.5: Informed Consent Review.
- In small groups, ask CBPR team members to read through the consent form and answer the questions on Worksheet 7.5.
- Come back to the larger group and discuss.

Leadership Follow-up

- ☐ Researcher will revise the research plan as needed.
- ☐ Researcher will revise the consent form as needed.
- ☐ See the appendix on page 117 for more discussion questions on ethics that you can discuss with the team.

Chapter 8: Collecting Data

Schedule a meeting for the leadership triad only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership (one being the researcher) and should include the entire CBPR team.

Chapter Goals

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

Introduction to Types of Data

- ☐ The researcher will present a brief introduction on data collection by asking team to turn to Chapter 8: Data Collection.
- ☐ Tell team that data is the "meat and potatoes" of the research, giving the project credibility.
- ☐ Explain the two types of data from the workbook.
- ☐ Remind the team which of type or types of data you have decided to collect.

Recruitment

- ☐ Ask team to turn to Worksheet 8.1: Recruitment Methods.
- ☐ Together read the paragraphs that introduce recruitment.
- ☐ State who the target participants are for your topic. (e.g. Black women ages 50+ with a mental illness that have Type 2 diabetes).
- ☐ Talk about who you might exclude from participating.
- ☐ Together brainstorm ways to recruit participants and write these on blackboard and/or worksheet.
- ☐ Once you have a list of recruitment methods, discuss advantages and disadvantages of each method.
- ☐ As a group decide what recruitment methods you will use and record this on the Research Plan on page 89.

Data Collection

- ☐ As a group, read the introductory paragraph to data collection.
- ☐ Use the discussion questions to make decisions about data collection
- ☐ Record your decisions on the Research Plan on page 89.

Engaging Participants

This engagement plan is completed with the CBPR team as a combination of large and small group activity.

- ☐ Ask CBPR team to find Worksheet 8.3: Engaging Participants.
- ☐ Ask the team to discuss questions 1-5 and make a decision on these items.
- ☐ Break into small groups and each group completes questions 6-14.
- ☐ Small groups join up with entire team to discuss and make final decisions on data collection.

Retaining Participants

Will you need to contact your participants again after the first visit?

- ☐ If yes, then discuss and decide on answers to questions 1 & 2 on Worksheet 8.4: Retaining Participants.
- ☐ Break into small groups to discuss questions 3-10.
- ☐ Come back to the larger group and discuss answers.
- ☐ Make a final decisions on retention strategies.
- ☐ Add this information to the Research Plan.

Leadership Follow-up

- ☐ Project Lead should write any tasks that need to be accomplished on the Action Plan on page 96.
- ☐ Researcher should incorporate any changes made during this chapter, including data collection, recruitment, engagement and retention into the Research Plan on page 89.

Chapter 9: Sustainability

Schedule a meeting for the leadership triad only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership (one being the health service provider) and should include the entire CBPR team.

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.

This session should be presented to the CBPR team early in the project, after the leadership has first met to talk about their visions for sustainability. As leadership, you have chosen a project that you are interested in continuing and are willing to support long-term. Community-based participatory research requires that the leadership to be committed to a lasting impact on the community.

- ☐ Ask team to turn to Chapter 9: Sustainability.
- ☐ Read the description of sustainability.
- ☐ Ask the team if they understand sustainability and encourage questions.
- ☐ Together read the description of ways to sustain your project.
- ☐ Ask the team to think about ways their own project might be able to continue and write these on Worksheet 9.1: Pros and Cons of Sustainability
- ☐ For each of those ways, think of the pros and cons of sustaining the project, including time and costs.
- ☐ Write the pros/ cons on the blackboard for all to see.
- ☐ If there is interest, form a Sustainability Committee.

Leadership Follow-up

- ☐ Revisit the conversation about sustainability regularly (once a month)
- ☐ Use the Sustainability Plan on page 67 to guide your efforts.
- ☐ See additional resources including Funding Suggestions on page 119), Grant Resources on page 120) and Other Funding Sources on page 124).

Sustainability Plan

Time Period	Need	Cost	To do list
Example: 3 months	*flyers*	*$2,000*	*Identify funding sources*

Chapter 10: Understanding Results

Schedule a meeting for the leadership triad only to discuss the chapter goals and complete the chapter assignments. This chapter should be facilitated by the researcher and should include the whole CBPR team.

Before presenting this chapter, the researcher will compile a summary of the results. This summary should be very short and written in layman's terms. If there are many results or if you use more than one method, break this into two or more sessions to avoid overwhelming the team. See Summary of Results Template in the appendix on page 91.

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.

Now that the data has been collected, we must understand what all of the information means. Analysis of data can be a time-consuming and complex process that is beyond the scope of this manual. Therefore, we are not including any specific information on data analysis in this chapter. The researcher on your team should be competent enough to analyze the data and should consult with research colleagues to confirm that analyses are done correctly.

- ☐ Ask the team to find the Worksheet 10.1: Understanding Results.
- ☐ Read the introductory paragraph together.
- ☐ Provide the team with a written summary of results.
- ☐ Present the results to the team.
- ☐ Ask the group the discussion questions on the worksheet.
- ☐ Take notes on discussion.
- ☐ Based on the feedback and discussion, decide as a team if you need to:
    - change the way the data is analyzed.
    - collect more data.
    - move on to the next chapter.
- ☐ Write needed changes on the Action Plan on page 96.

Chapter 11: Sharing Results and Taking Action

Schedule a meeting for the leadership triad only to discuss the chapter goals and complete the chapter assignments. This chapter should be co-led by two members of the leadership one being the health service provider and should include the entire CBPR team. Leaders will bring the summary of results, as discussed and revised (if needed), from Chapter 10.

Chapter Goals

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

An important component of research is to share the information that has been obtained. Information can be shared in many ways, such as through presentations, flyers or social media. Within the CBPR structure, we understand that we are bringing many cultures to the table that have different views of sharing information. The results of this research are designed to share with all interested communities.

- ☐ Read the introductory paragraphs in Chapter 11: Sharing Results chapter in the workbook together.
- ☐ Review the results summary from Chapter 10 to make sure everyone remembers and understands.
- ☐ Use the discussion questions on Worksheet 11.1: Sharing Results and Taking Action to talk about dissemination and action. If needed, break up the results into parts and ask the discussion questions separately for each part of the results.
- ☐ As a team, decide which suggestions you are willing to pursue, which are feasible within the given time and which will have the greatest impact on the community.
- ☐ Based upon this discussion, complete the Dissemination Plan on page 70 and Community Action Plan on page 71 as a team.

Leadership Follow-up

- ☐ Project Lead should write any tasks that need to be accomplished on the Action Plan on page 96.

- ☐ Researcher should incorporates plans for dissemination and action into the Research Plan on page 89.

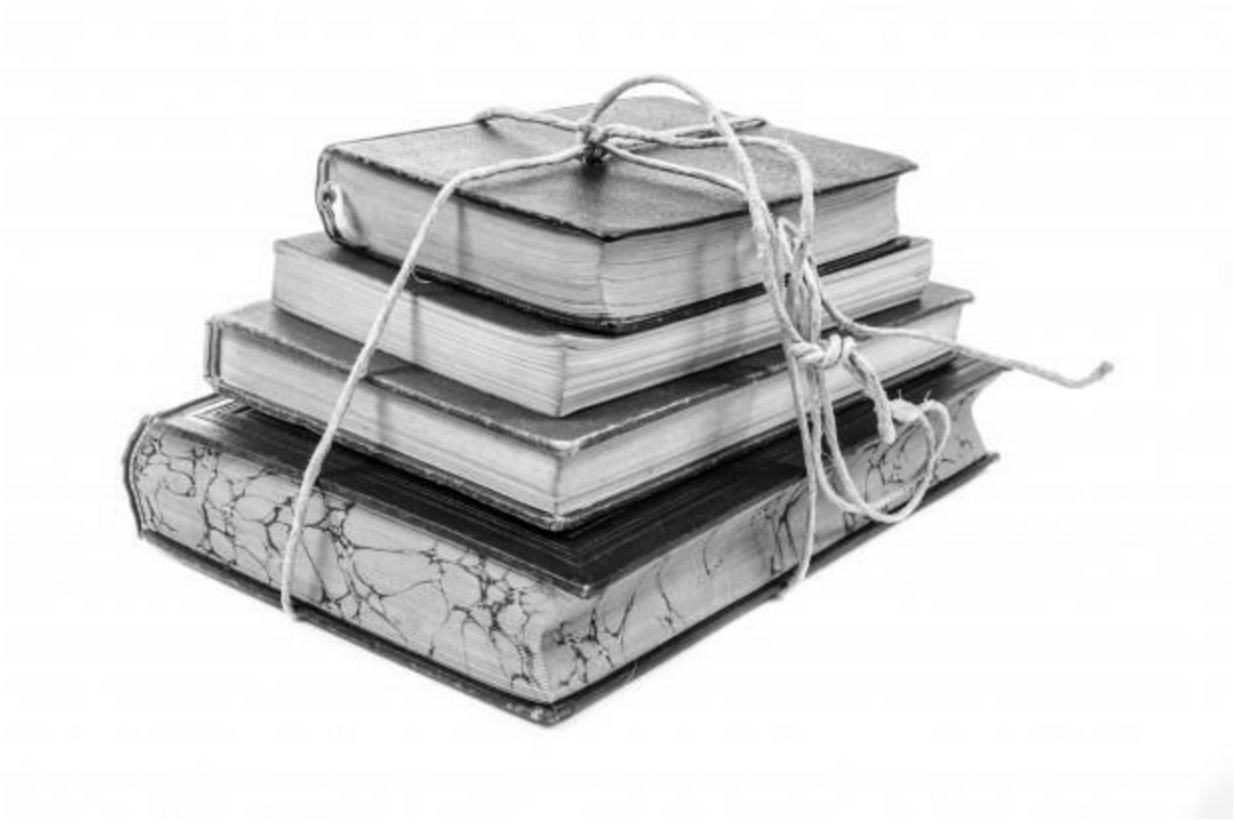
Dissemination Plan

Which people and/or organizations will you share results with?	What methods will you use to share these results?	What do you hope the people/ organization will do with the results?	Which CBPR members are responsible for completing this?
e.g. Agency Y	*Presentation for case managers of Agency Y*	*Pass on resources to African American patient/clients*	*Ronnie and Sue will make up presentation*

Community Action Plan

What actions will your team will take based on your results?	What steps will you need to complete to take this action?	What resources you will need to take this action?	Which CBPR members are responsible for completing this action?
e.g. Get Agency X to start offering the solution we designed	*1. Set up a meeting with CEO or Agency X* *2. Train Agency X staff* *3. Provide technical assistance during implementation*	*1. Professional printed training guide* *2. Trainers*	*Mary*

Appendix



Templates

These templates provide guidance for many of the research activities.

Recruitment Templates

Phone Interview Script
[Name of CBPR Project/Team]

Interview taken by: _____ Date: _____

Position overview: [Brief description of the project and the team's goals]

If you are still interested, please answer the following questions in order to determine if you are a good fit. If you are uncomfortable with any of the questions, you do not have to answer.

Requirements: [Specific description of the persons needed to accomplish CBPR goal] Example: We are looking for people who fit these specific criteria: African Americans with mental health challenges or health care providers who serve African Americans.

Are you either of those?

Please note, if you are selected, you will not be a research participant--- you would be a research partner [Explain briefly what this means]

Commitment: [Outline meeting schedule day, time, and frequency].

Compensation: [Be specific with payment and method of payment]

Community Based Participatory Research Application

We are looking for team members with a diversity of backgrounds and perspectives. Please provide us with answers to the following questions.

1. Name:_____
2. Primary Telephone # _____(Please circle: Home/Cell/Work)
3. Email:_____

   If you're not available, would you like a message to be left: ☐ Yes ☐ No

   Age: What is your age? _____

   Gender: ❑Male ❑Female ❑Other

4. Race: --- **(check all that apply)**
   - ❑ American Indian/Native Alaskan
   - ❑ Asian
   - ❑ Black/African American
   - ❑ Native Hawaiian/Other Pacific Islander
   - ❑ White
   - ❑ Other Race. Please name your race(s) _____
   - ❑ Refuse

5. Ethnicity: Are you Hispanic or Latino?
   - ❑ Yes
   - ❑ No

6. Marital Status: What is your marital status?
   - ❑ Single, never Married
   - ❑ Married or domestic partnership
   - ❑ Divorced
   - ❑ Separated
   - ❑ Widow

7. Education: What is the highest degree or level of school you have completed?
   - ❑ Some high school, no diploma
   - ❑ High School Graduate, diploma or the equivalent (GED)
   - ❑ Some college, no degree
   - ❑ Trade/technical/vocational training
   - ❑ Associate degree

- ❑ Bachelor's degree
- ❑ Master's degree
- ❑ Professional degree
- ❑ Doctorate degree

8. Employment Status. Are you currently…?
   - ❑ Employed for wages:
   - ❑ Full time
   - ❑ Part time
   - ❑ Unemployed
   - ❑ A student
   - ❑ Military
   - ❑ Retired
   - ❑ Unable to work

9. Sexual Orientation: How would you identify your sexual orientation?
   - ❑ Heterosexual
   - ❑ Gay
   - ❑ Lesbian
   - ❑ Bisexual
   - ❑ Other

10. Do you work in a professional where you provide mental health services?
    a. ☐ Yes ☐ No
11. Do you work in a profession in which you provide mental health services?
    ☐ Yes ☐ No

12. Do you currently receive mental health services? ☐ Yes ☐ No
    If yes, what agency do you receive mental health services from? (We will not contact that agency)
    _____

13. Do you have any physical disabilities or medical conditions that you receive regular treatment for? ☐ Yes ☐ No

14. What hospital/clinic/agency do you receive primary care/ medical services?
    _____

15. Do you have a family member with serious mental illness? ☐ Yes ☐ No

If yes, are you involved in helping them obtain health care, both mental and physical?
□ Yes □ No

16. Do you have any personal experience with the following?
    - Substance Abuse: □ Yes □ No □ Refuse
    - Military: □ Yes □ No □ Refuse
    - Criminal History: □ Yes □ No □ Refuse
    - Homelessness: □ Yes □ No □ Refuse

17. Do you live in the city of [city name]? □ Yes □ No
    If so, what neighborhood? _____

18. Do you have any experience doing research? □ Yes □ No If yes, please describe:
    _____
    _____
    _____
    _____

19. Do you have any work experience or other life experiences that would be relevant to this position? □ Yes □ No If so, please list
    _____
    _____
    _____

20. Why would you like to become a member of the [CBPR Project/Team Name]?
    _____
    _____

21. Do you prefer to work alone or with a team? _____

Thank you for taking the time to fill out this application.

Sample Interview Questions

These interview questions provide a starting point for interviewing potential CBPR members. You want to target individuals that will help you complete CBPR team goals and these questions give you an idea of whether the applicant will work well with others, his/her commitment level and his/her understanding of the proposed project. Pleas add your own questions or revise these as needed.

1. Tell me about a project that you have been involved in?
   Did you complete the project?
   What was the outcome from the completed project?
2. What do you think you could add to this project?
3. What are some challenges that you have overcome?
4. How would you involve other members of the team when an important decision needs to be made?
5. Tell me about what motivates you?
6. What frustrates you?
7. How do you handle frustration?
8. Would you be available on [Day] at [Time] on a regular basis?

References

Please provide information for three references that we can contact to discuss your suitability for the project.

Name:
Phone:
Email:
Length of time known:
Relationship:

Name:
Phone:
Email:
Length of time known:
Relationship:

Name:
Phone:
Email:
Length of time known:
Relationship:

Name:
Phone:
Email:
Length of time known:
Relationship:

Reference Check Form

Name of Applicant: _____
Telephone Number of Applicant: _____
Name of Reference: _____
Telephone Number of Reference: _____
Relationship to Candidate: _____

1. How do you know the applicant?

   _____

2. How long have you known the applicant?

   _____

3. How well does the applicant get along with others?

   _____
   _____
   _____
   _____
   _____

4. On this research project, the applicant would be working with a team to develop and carry out a research project to improve the health care of African-Americans with serious mental illness. The applicant would be meeting regularly with the team and giving project input based on their personal experiences. How do you think this person would perform on such a project?

   _____
   _____
   _____
   _____
   _____
   _____
   _____
   _____

Reference Check conducted by:

Name: _____ Date:_____

Agenda

Agenda
[Name of CBPR Project]

[Date]
[Time of Meeting]
[Location]
[Meeting #]

I. Review/Approve Last Meeting Minutes

II. [Fill In the Blank]

III. [Fill In the Blank]

IV. [Fill In the Blank]

V. Adjournment and Payment

MINUTES

[Name of CBPR Project/Team]

Date:[Fill In the Blank]

The meeting was called to order by [Name of Facilitator and Time]

Approval of Minutes
The minutes were read from the [Previous meeting date] and [approved and/or changed].

Old Business
[Fill In the Blank]

New Business

[Fill In the Blank]
[Fill In the Blank]
[Fill In the Blank]

Committee Reports
[Fill In the Blank]

Announcements
[Fill In the Blank]

Next Meeting
Date and time: [Fill In the Blank]

Receipt for Compensation

Community-Based Participatory Research Team

I, _____, hereby acknowledge that I have received total compensation in the amount of $_____ for my work on the CBPR team.

I received this compensation as follows:

Number of Cards/Bills	**Denomination**	**Total**	**Gift Card Number(s)** **Please be sure to provide the number for EACH card.**
	$ gift card	$___	Card#1: _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _
	Other gift card amount	$___	Card#1: _ _ _ _ _ _ _ _ _ _ _ _ _ _ _ _

Signature: _____ Date: _____

Attendance Tracking Sheet

CBPR Attendance Tracking

Period/Time _____ _____

NAME	February			March				April					May			

Memorandum of Understanding Template

This is a Memorandum of Understanding between Organization A and Organization B

This Memorandum of Understanding sets forth the working relationship of these organizations including their roles and responsibilities as a part of their involvement in the [PROJECT NAME].

Program Objectives/Accomplishments

Specific Aim 1:
- Objective 1:
- Objective 2:

Specific Aim 2:
- Objective 1
- Objective 2:

Responsibilities of Organization A

1.
2.
3.
4.
5.
6.

Responsibilities of Organization B

1.
2.
3.
4
5.
6.

Financial Arrangements

Organization A will receive XX amount of funds during the time period (month/year- month/year).

The funds are for: (list items and amounts)

To obtain the funding, Organization A will submit monthly invoices. Payment for invoices will be made within 30 days.

Memorandum of Understanding Amendments

The agreement shall be renewed annually by the signatories.

Termination of Memorandum of Understanding

This agreement may be terminated by either party provided not less than thirty days (30) written notice of intent to terminate is given and an opportunity for prior consultation is provided. In the event of termination, accounts shall be reconciled as of the date of termination.

Signatures

This Memorandum of Understanding is entered into on
_____(date)

Signature:_____ (Organization A)
Signature:_____ (Organization B)

This memo of understanding was adapted from Community-Campus Partnerships for Health (2013).

Literature Review Template

A literature review summarizes the published research on a specific topic. The review helps a researcher become familiar with the topic and may help identify gaps in the research that your project can fill. The review should be brief (1-2 pages) and should be presented mainly using detailed bullet points.

Introduction

- Define the review topic
  - Ex- health care disparities for homeless African-Americans with mental illness within the past 15 years
- Summarize the type and number of research findings available for review

Body

- Organize results by themes/ areas
  - Disparities in primary care, disparities in hospital care, disparities in mental health care
- Highlight studies with the most rigorous scientific designs

Conclusion

- Summarize the key findings of the research in general
- Identify gaps in the research and bullet point opportunities for future research

References

- Keep a list of all citations (cite in text as well)

Project Information Template

Welcome to the Team!!

Project Title:

Project Description: This community-based participatory research (CBPR) project will address…….. [provide a brief description of your proposed project].

CBPR members are viewed as active participants during all stages of research and are provided with training and support to complete their projects.

Contact Information for Project Leaders

Name, Title
email address
phone number

Name, Title
email address
phone number

Meeting Information

Meeting Date/Time:
Meeting Location:
Compensation:

Please contact [insert name of project leader] in advance if you will not be able to attend a meeting.

Research Plan

Research Question (s):

Hypotheses

1.
2.
3.
4.
5.

Research Methods (provide description of methods)

Recruitment Plan

Engagement/Retention Plan

Data Collection

Sustainability

Dissemination

Consent Document Template and Explanation

This is a consent form template to guide you through the various elements of consent. Instructions are in italics and [brackets] indicate fillable information.

Introduction

We are asking you to participate in a research study titled [TITLE]. We will describe this study to you and answer any of your questions. This study is being led by [NAME OF INVESTIGATOR, DEPARTMENT NAME at ORGANIZATION NAME].

Purpose

The purpose of this research is to….

In non-scientific language, state the purpose of the research.

Procedure

We will ask you to….

Explain what will be happening to the participant or what s/he will be asked to do during the study, including how much time it will take.

Risks and Discomforts

Risks or discomforts that could result from participating in this study include…..

Describe any risks/discomforts including emotional risks, social/economic risks, legal risks or physical risks

Benefits

The benefits of participating in this study include…..

Describe the probable benefits of participation in the research.

The expected benefits to society or scientific knowledge from this research include…

For example, "…information from this study may benefit other people now or in the future…" or "…we hope to learn more about _____ …")

Compensation

Participants will be compensated $XX in the form of ……..

Indicate whether the participant will receive compensation or payment or extra credit for being in the study. If participants will not receive any compensation, state that there is no payment or course credit for taking part in the study. If the research involves experimental treatment/therapy/intervention, describe any non-experimental alternatives that may be available.

Audio/Video Recording

If audio and/or video recording devices will be used, explain why the recordings are needed for the research and what will be done with them upon completion of the research.

Privacy/Confidentiality/Data Security

We will protect participant's privacy and confidentiality by…..

Explain briefly how you will protect the participant's privacy and/or confidentiality. This includes whether you will de-identify information, where you will store your data to keep it safe (both physically and electronically) and who will have access to data.

Voluntariness

Your participation in this study is voluntary and you may decide not to participate or decide to stop participating at any time.

If completing all research materials (e.g., answering all survey or interview questions; meeting a minimal requirement of entries in a weekly/monthly log) is required for participation, please state that here.

Questions

Please ask any questions you have now. If you have questions later, you may contact [INVESTIGATOR'S NAME] at [EMAIL ADDRESS] or at [PHONE NUMBER]. If you have any questions or concerns regarding your rights as a subject in this study, you may contact the Institutional Review Board (IRB) at [PHONE NUMBER].

Indicate if the participants will be given a copy of this form to keep for their records, or some other information sheet.

I have read the above information, and have received answers to any questions I asked. I consent to take part in the study.

Signature _____ Date_____

Summary of Results Template

Title of Project: _____

Instructions: Present findings in clear, understandable bullet points that are 30 words or less. Explain statistics, describe in simplified terms (e.g. this means that people in the control group were much more likely to be hospitalized).

Finding 1

African-Americans who worked with peer navigators visited the doctor more often than the control group.

Finding 2

African-Americans who worked with peer navigators said that they were more satisfied with health services than the control group.

Finding 3

African-Americans in this study were not very satisfied with services overall. Only 20% said they were satisfied or very satisfied.

Finding 4

Focus group participants felt that dental care was severely lacking in the community.

Research Project Budget

CBPR Compensation	Estimated	Actual	Notes
CBPR Team Compensation	$500.00		
Total	**$500.00**	**$0.00**	

Research Assistants	Estimated	Actual	Notes
Person 1	$500.00		
Person 2	$500.00		
Total	**$1,000.00**	**$0.00**	

Participant Costs	Estimated	Actual	Notes
Focus Groups	$500.00		
Surveys	$300.00		
Total	**$800.00**	**$0.00**	

Refreshments	Estimated	Actual	Notes
Food	$300.00		
Drinks	$100.00		
Paper supplies	$100.00		
Total	**$500.00**	**$0.00**	

Other Supplies	Estimated	Actual	Notes
Printing Costs	$300.00		
Total	**$300.00**	**$0.00**	

Total Expenses	Estimated	Actual
	$3,100.00	**$0.00**

Action Plan

The Action Plan is your "To-Do" list. The Project Lead should be responsible for making sure all items get done and tracking completion.

Action Item	Deadline	Person/ People Responsible For Completion	Completed?
Ex- Recruitment Flyer	*July 1*	*Researcher*	*yes*

Resources

This section provides additional resources to use during your project.

Research Topics

Here are some research topic ideas for CBPR teams to help generate ideas.

Understanding the Problem

1. What are the problems that older African-Americans with mental illness have in accessing diabetes treatment?
2. What are the obstacles to accessing specialty doctors (podiatrists, dentists, endocrinologists, etc.) for African-Americans with serious mental illness?
3. How can physicians, psychiatrists and other health care workers face improve their communication with one another to best meet the needs of African-American with serious mental illness?
4. What problems do African-Americans with serious mental illness have with understanding their medical records and sharing their medical records/ medical histories with multiple health providers?
5. How do African-Americans with serious mental illness deal with traveling between multiple health locations to get treatment?
6. What medication side effects are most troubling for African-American with serious mental illness? What leads them to stop taking medications or getting treatment?
7. How much do African-Americans agree with their given mental health diagnoses and how does that impact their treatment participation?
8. How are African-Americans with serious mental illness addicted to painkillers being treated by healthcare providers?
9. How do African-Americans with serious mental illness feel about taking medication to treat physical and mental health care needs?
10. What are African-Americans with serious mental illness and physical health concern about not getting their medication?
11. How do African-Americans with post-traumatic stress disorder experience the care provided through integrated care? (Is it retraumatizing?)
12. What barriers to care do African-Americans with anorexia/bulimia experience within the integrated care system?
13. How do primary care physicians address obesity in African-Americans with serious mental illness?
14. Why do African-Americans with serious mental illness frequently utilize emergency rooms for healthcare?
15. What types of discrimination do African-Americans identify in the health care system?

16. What does a culturally competent health provider look like for African-Americans with serious mental illness?
17. How are sexual health needs for African Americans with serious mental illness being met?
18. What alternatives do people use to psychiatric medication?
19. How do faith-based organization impact and play a role in stigma?

Designing a Solution

1. Nutrition education for African-Americans with serious mental illness.
2. Eliminating stigma by medical professionals towards African-Americans with serious mental illness.
3. Training program for physicians and psychiatrists to interact with African-Americans with serious mental illness.
4. Self-advocacy training program/ self-advocacy kit for African-Americans with serious mental illness (how to talk to your doctor; how to evaluate and challenge your medical records)
5. Intervention to get African-Americans with serious mental illness to get help with physical and mental health issues.
6. Addressing community assessment needs for hospitals that serve African-Americans with serious mental illness.
7. Developing a "therapy bus" to travel to underserved neighborhoods and provide mental health/ physical health topics/services
8. Education program for religious/spiritual leaders about assessing and referring people with serious mental illness for treatment
9. Family intervention to improve participation in treatment
10. Peer intervention to encourage medication use
11. Parenting classes and support groups for African-Americans with serious mental illness
12. Cultural awareness program for health providers and leaders of health care organizations
13. Education program on when to use/ not use ER services
14. Mental health screenings through religious communities
15. Suicide prevention/ education program specific for African-Americans
16. Social support program for people with alcoholism
17. Lifestyle coaching for people involved with drugs/ gangs
18. Trust-building between patients and physicians
19. Ethics trainings for health providers led by people with lived experience
20. Medication adherence program/ medication monitoring designed to fit lifestyles of people with addiction

Testing a Solution

1. How well do peer navigators work with assisting African-Americans with PTSD?
2. Do needle exchange programs work well in addressing the needs of African-Americans with serious mental illness?
3. How successful are free transit cards and van transport programs with African-Americans with serious mental illness?
4. Do incentive programs increase or decrease participation in health care from African-Americans with serious mental illness?
5. Do special diets manage symptoms among African-Americans with bipolar disorder?
6. How well do outreach programs work when addressing physical and mental health concerns of African-Americans with serious mental illness?
7. How well does meditation work for African-Americans with serious mental illness?
8. How well does mindfulness work?
9. How do abstinence only programs compare to harm reduction for substance abuse?
10. How do WRAP plans work for African-Americans?
11. How well does exercise work to improve symptoms of serious mental illness?
12. Does collaborative documentation help improve therapeutic alliance with health providers?
13. Do patient portals and electronic access to health records help involve African-Americans in treatment?
14. How does supported employment work for African-Americans with complex medical issues?
15. Do nurse help lines improve care?
16. Do diverse healthcare workers improve care?
17. Do transitional living centers promote independent living?
18. Does mental health first aid for community members improve treatment-seeking for African-Americans?
19. Does trauma-informed care in integrated health increase treatment engagement?

Tips for Working with Agency Partners

Here are possible steps for pursuing an agency partnership.

- Select the community agency that you would like to pursue a partnership with.
- Identify the individual/department liaison from the community agency and then meet to discuss the project.
- Find out whether the agency has an institutional review board and what the process would be to get your research approved.
- Obtain formal approval from the agency to partner in research.
- Sign a Memorandum of Understanding (see appendix on page 85)
- Obtain or create a clear and detailed description of the solution/ intervention, if you will be testing a solution.
- Request a brief tour at the community agency.
- Decide which of the above you will do and who will complete each task.

Sample Group Rules

- Show respect to all individuals involved in this project.
- Allow others to complete their thoughts without interruption. Please raise your hand to participate.
- Be mindful of 2 minute time limit so everyone has an opportunity to speak.
- Keep an open mind and do not judge opinions in a negative manner.
- Silence all cell phones and give your attention to the group rather than to electronic devices during meetings.
- Any personal information about others should not be shared in board meetings without that person's consent.
- In consideration of all group members, please keep colognes, body oils and perfumes to a minimum.
- Be professional.
- Please arrive on time.
- Keep focused on project goals.
- No profanity.
- No loud conversations in hallways or outside of building.
- Please make every effort to attend all meetings.

Reasonable Accommodations

CBPR research is very different than traditional forms of research. One distinct and obvious difference is that this research type involves individuals that may not be familiar with the specifics of science. In addition, people with serious mental illness may experience symptoms that interfere with their ability to participate. However these same individuals bring very unique insight into the research arena. In order to ensure the best possible participation in the research project it will be necessary to make accommodations for CBPR team members.

Here are some examples of reasonable accommodations:

Reminder calls for meetings: To avoid confusion about whether or not the team will meet on a particular week it may be necessary to call and remind some or all team members.

Regular breaks during sessions: Depending on the topic some tasks can be mentally taxing and you may begin to lose the attention of some or all of your CBPR team members. The break times may vary for this reason.

Personal check-ins to provide support for members: Personal check-ins help the team to get to know one another better. Persons with lived experience in dealing with mental health challenges may need a little more support.

Leaving early: Some CBPR team members will have doctor visits, housing counseling, case management appointments or other related needs. It is important to let them know that this is a supportive environment. You may also need to follow up with individuals privately.

Excused Absences: Many situations occur that will cause CBPR team members to miss meetings. Although it is important to be supportive, if this is a chronic occurrence it should be addressed privately.

Allowing different seating arrangements: It may be necessary to make accommodations for team members that have mobility concerns, room temperature needs, lighting challenges etc.

Providing materials orally: Some CBPR team members may have challenges with reading and/or sight. It will be important to ensure that each team member will be able to participant equally.

Private meetings with leadership team member/s: CBPR team members often need to communicate questions and concerns outside of the scheduled meeting

times. Many conflicts can be resolved in private sessions. It is also important to note that these meetings may also be initiated by the leadership.

Up to date sessions: There may be occasions when time is set aside before or after meetings to bring team members up to speed on events that were missed. Some of these sessions may take place on days that are scheduled outside of the meetings. It is important that no one person feels left behind.

Adjustments in day and time: It is important that a day and time be assigned for consistency, but depending on participation levels and scheduled timelines, try to be as flexible as possible.

Consent Document Sample

Public Opinions on Suicide Focus Group

The purpose of this study is to explore public opinions about suicide. As a study participant, I will spend approximately 90 minutes in a focus group discussing my perceptions as well as the general public's opinions about suicide. I understand that my participation in this research project is voluntary.

For study participation, I will receive payment in the amount of a $50 prepaid gift card. I understand that I may decide to stop participating in the focus group at any time during the group's meeting and will still receive payment for my participation.

All identifying information will only be used for study purposes. It will not be sold to anyone and will not be used to contact me regarding another study. My responses will be written down, but my name will not be connected with any of my responses. **Family, friends, or health care providers will never know about my participation or my contributions in the focus group discussions.** This information will be securely stored in a locked file and will not be accessible to anyone other than the Principal Investigator and research team. I understand that any information recorded for the purpose of this study will be destroyed after six years.

This research presents no risks other than what I might feel from thinking about the topic of discussion and the questions that are asked. A psychologist, Dr. XX, is available for me to talk to, free of charge, to discuss my situation or my feelings, which may be due to my participation in this study. Dr. XX can be contacted at [PHONE NUMBER]. Any further questions about the research and my rights as a participant will be answered if I contact the project director, Dr. XXX at [PHONE NUMBER].

I understand that the ORGANIZATION is not responsible for any injuries or medical conditions I may suffer during the time I am a research participant unless those injuries or medical conditions are due to the ORGANIZATION's negligence. I may address questions and complaints to [NAME OF IRB DIRECTOR] or the Institutional Review Board at [PHONE NUMBER].

I have read the material above and any questions I asked have been answered to my satisfaction. I agree to participate in this activity, realizing that I may stop participating without penalty at any time

*I have received a copy of this consent form.

_____ _____

Participant Date

Tips for Engaging the Team in Recruitment and Data Collection

This is a resource for the leadership to use for engaging the CBPR team throughout the process.

For Key Informant Interviews

- Have the CBPR team to brainstorm ideal characteristics of key informants. (work in health care, have a family member with serious mental illness, etc.)
- Ask the CBPR team to consider their social network and whether they know anyone who could serve as a key informant.
- Ask CBPR to distribute flyers or advertisements to recruit participants.
- Ask CBPR team to formulate the list of interview questions.
- Have CBPR conduct key informant interviews in a group setting (if key informants are comfortable with this).
- Invite CBPR team to help with sorting interview responses into themes.
- Present findings and analyses to CBPR team and engage in discussion about what these findings/themes mean to them.

For Focus Groups

- Have the CBPR team to brainstorm ideal characteristics of focus group members (work in health care, have a family member with serious mental illness, etc.).
- Ask the CBPR team to consider their social network and whether they know anyone who could serve as a focus group member.
- Ask the CBPR members to hand out flyers or publicize focus groups on social media.
- Ask CBPR team to formulate the list of interview questions for the focus groups.
- Have CBPR help with focus groups (set-up, clean-up, greeting, transcribing, etc.) based on interest and ability.
- Invite CBPR team to help with sorting focus group responses into themes.
- Present findings and analyses to CBPR team and engage in discussion about what these findings/themes mean to them.

For Surveys

- Have CBPR team generate the questions to include on the survey.
- Ask CBPR team test out the survey and look for:
    - Errors
    - Clarity of wording
    - Time needed take the survey
    - Accommodations that might be needed

    - Cultural sensitivity
- Ask the CBPR team to consider their social network and whether they know anyone who could might participate in the survey.
- Ask the CBPR members to help recruit participants to take the survey.
- Present findings and analyses to CBPR team and engage in discussion about what these findings/themes mean to them.

For Observational Research

- Ask the CBPR team discuss how the observations will be carried out and how practical and/or feasible the observation will be.
- Ask the team to help with recruitment of participants.
- Ask the team to help obtain consent documents.
- Have the team help with making the actual observations or review of records.
- Present findings and analyses to CBPR team and engage in discussion about what these findings/themes mean to them.

For Windshield Tours

- Ask CBPR team advises on neighborhood, time, days, persons of interest etc.
- Seek CBPR members who have personal connection within the community organization that you would like to tour or establish the relationship with
- Present findings and analyses to CBPR team and engage in discussion about what these findings/themes mean to them.

Tips for Focus Groups

Before You Begin

What is the purpose of your focus group? State the focus in one sentence, for example, "How can health care providers improve dental care for African Americans with serious mental illness?" Make sure all questions are about this topic and not just based on curiosity of the research team.

Focus groups are a big time commitment. Make sure you have a team member who can be organized in managing the screening and recruiting. Make sure you have the space that you need, a skilled person to moderate the group, and a plan for analyzing the information before you start.

Question Development

- Write a brief introductory script to read before the questions about the purpose of the group.
- Plan about 10 questions.
- Use open-ended questions (not closed questions) to get as many perspectives as possible
    - Open-ended Question: What would make it easier for you to get to the dentist?
    - Closed Question: Do you like to go to the dentist?
- Lead with general questions to get people talking and then go to more specific or sensitive topics.
- Use short questions with simple language.
- Make a short (less than 10 questions) demographic questionnaire (age, race, income, etc.) for participants to complete when they arrive.
- Have several people test out the questions and give feedback.
- Submit for IRB approval.

Screening and Recruitment

- Decide who you will include and exclude as participants.
- Design a flyer and a script to use for recruitment.
- Screen participants thoroughly. Ask them the screening questions over the phone. You will want to make sure they clearly understand the purpose of the research and what a focus group is. Make sure they know how to get to your location and that are comfortable speaking in a group setting.
- Try to get a diverse group that represents many different perspectives. You can ask some screening questions to make sure you have a diverse group.
- You might want some participants in separate groups. For example, patients might not feel comfortable sharing their concerns about dentists if there are dentists in the same focus groups.

- Keep an organized list of participants and potential participants. Keep good communication with participants.
- Over-schedule focus groups because there are usually a few people who do not show up.
- Give reminder calls or emails the day before the group.

The Basics

- Make sure your focus groups have 6-10 individuals
- Schedule groups for 60-90 minutes
- Schedule 3-6 focus groups overall
- Stop scheduling groups when you are no longer hearing any new ideas or perspectives in the groups
- Have the group in a comfortable room around a table
- Have a moderator and assistant moderator
- Have food and drink
- Set a start time 15 minutes before to allow for latecomers, paperwork, restroom visits, etc.
- Write participant numbers on name tags or name tents
- Test out audio-recording device

Focus Group Checklist

- ☐ Snacks
- ☐ Drinks
- ☐ Paper supplies (cups, napkins, plates)
- ☐ Money/ gift cards
- ☐ Informed Consent and Copy of Consent
- ☐ Demographic questionnaire
- ☐ Focus Group questions
- ☐ Resources
- ☐ Audio recording device
- ☐ Pens/pencils

The Moderator

A moderator should have the following abilities

- Good listener
- Respectful of opinions
- Knowledgeable about the topic
- Does not ask leading questions

- Does not share personal opinions
- Can manage people within the group and keep on track

In addition, the moderator should:

Practice moderating- have a practice group with your research team

- Think about follow-up questions- Can you tell me what you mean? Can you give me an example?
- Be prepared to repeat the questions using different language.
- Occasionally paraphrase or summarize participant responses.
- Reinforce participants with positive body language.

The assistant moderator should:

- Greet participants
- Take notes
- Collect consent forms and questionnaires
- Make sure audio equipment is working
- Assist with any special needs of participants

The Session

Beginning

- Thank them for coming
- Allow them to get food, drink, use the restroom
- Ask them to turn phones off
- Explain the consent document and group agenda
- Answer questions
- Go over ground rules
  - Ask participants to be respectful of other opinions
  - Tell them there are no right or wrong answers
  - Ask them to take turns
  - Ask them to stay on topic
  - Ask them to keep information confidential
  - Remind them that this is a research group, not therapy

Middle

- Do not rush, use silence as needed
- Transition smoothly from one question to another
- Keep focus on the questions

End

- End on time

- Ask if there are any final thoughts
- Hand out compensation.
- Give out any resources that might be useful for participants related to the topic.
- Make sure everyone is emotionally okay before leaving.
- Debrief after session with assistant moderator to evaluate how the group went and prepare for the next one.

Managing Data

- Store transcripts, notes and audio recordings in a secure place where they will be confidential. Make sure that they are clearly labeled with the date and name of the focus group.

Analyzing Data

Allow money and time for transcription and coding.

There are many ways to code data. This is one suggested low-tech way.

1. Print out two copies of the transcripts.
2. Identify bytes.
    a. Two independent raters use highlighter to underline distinct bytes of information. A "BYTE" is a distinct and limited piece of information. For example:
        - Research gave me a sense of purpose.
        - The leaders were not available.
        - We didn't have enough time.
    b. A passage such as "Research is very difficult, but important to pursue" is two bytes and should be separated as such.
    c. c. The two raters should compare to see whether they have identified the same bytes and resolve discrepancies before proceeding.
3. Identify themes.
    The themes should be based loosely on the questions, but the coders should allow themes to emerge from the data. Start with a list of possible themes (see example below) based on questions and familiarity with the data. Create new additional themes from bytes that do not fit into themes.
    Example Themes:
        - Benefits of the research
        - Challenges of the research
        - Conflict resolution strategies
        - Divisions of work

4. Each rater should go back through the first transcript and code each byte into themes. In a separate file or on a notecard, list each of the bytes verbatim from the transcript under each of the themes. Sort notecards into theme pile or copy into a spreadsheet.

5. Determine interrater reliability.

Have two raters sit down and rate the same survey.

a. Take two lists from independent raters: call them A and B.
b. Determine the total number of identical bytes reported by A and B.
c. Determine the total number of identical bytes reported by A but NOT B.
d. Determine the total number of identical bytes reported by B but NOT A.
e. Reliability = total A and B/ (total A and B + total A but not B + total B but not A)

6. Raters decide together whether themes should be eliminated, added or combined. Discuss differences between the coding decisions. If reliability between the raters is more than 75%, then proceed with coding independently.

7. Raters review the coding of all transcripts once they are finished to determine the reliability score and agree on a final version of the coding (resolve differences).

Tips for Surveys

Beware: Surveys take more time than you think.

- Clearly state the purpose of the survey in one or two sentences.
- Decide what method you will use: mail, telephone, face-to-face interview, web-based, paper-and-pencil
- How long do you have? Attention span is short— probably 15 minutes or less.
- Decide what sampling strategy you will use. Examples are:
    - Random: every person has the same chance of being chosen for the survey
    - Stratified: a random sample from several different subgroups (dentists, patients, dental hygienists)
    - Convenience: whoever you can find easily
    - Snowball: existing participants help recruit more participants
- Use questionnaires that have been used in other research before if they exist, but considering adding some of your own questions if you can't find a questionnaire in the literature (the researcher can help you with this)
- Decide who will qualify for the survey and who will not (do they need to be able to read, speak English, be over age 18, have experience with health insurance, etc.)
- Consider placing questions to see if people are paying attention (Example: Select answer choice c for this question)
- Make sure you have enough answer choices for questions. You should usually have at least 4 answer choices. Avoid asking yes or no questions.
- Make sure you are asking a question that someone can realistically answer.
- Don't ask leading questions.
- Avoid open-ended questions or questions that will be difficult to analyze later.
- Consider allowing some space for comments though.
- Allow "don't know" or "not applicable."
- Make sure language is understandable.
- Make sure you ask everything you need to—you can't go back.
- Avoid double-negatives because they are very confusing. For example: "I disagree that teachers should not go on strike."
- Make rough draft of the survey.
- Have several people test it out, preferably people who are similar to your participants. Ask them to be very critical.
- Read the survey out loud to someone and also have at least 3 people complete on their own and give feedback.

- Do all the survey questions serve the stated purpose? What will you do with the information you get from the survey questions? How will it help others?
- The researcher should have a plan for analyzing the data BEFORE you start the survey.
- Revise as needed and then have people review it again. Is it too long?
- Submit to IRB.

Online Surveys versus In-Person Interviews

Note: In-Person interviews are administered by a survey proctor who asks the questions and records the answers. The answers can be recorded onto an online platform or completed on pencil and paper.

Disadvantages of Online Surveys

You may need to pay for the survey platform.

Online surveys can be challenging to set up the survey if you are not familiar with the online survey software.

There are no interactions or opportunity for clarification if the participant does not understand the questions.

People with low literacy or low computer literacy may not participate or may not have valid results.

You must figure out a way to pay participants that does not compromise their confidentiality.

Participants may be more likely to pick random responses in online survey or have shorter attention span.

Others?_____

Advantages of Online Surveys

You don't need to manually enter data into the computer.

If it is a sensitive topic, participants may be more honest in online survey.

Online surveys are usually cheaper and faster to administer.

Others?_____

Ethical Issue Discussion Questions

Facilitators can use these questions to generate discussions about their research project and get team members to think more about ethical issues.

Should participants be able to drop out of the survey at any time and still get paid?

What does confidential mean?

What does anonymous mean?

How will our research results benefit the community? Is it worth the resources to do this project?

How much should the community be involved in the technical parts of the research (design, data collection, analysis)?

How will we divide up the work responsibilities in a fair way?

How do you present results to the community? Do you hold back findings that might make the community or service agency look bad?

How do you deal with unexpected results? What if I don't like the research results?

How can you make sure that you don't bias the results of the research?

How can you take off your "provider hat" or "human hat" to do the research?

How can you make sure that participants understand the informed consent?

How will you store the data and who store the data?

Does the research team have enough training to do the project? If we don't what should we do?

What if you know the people who will be research participants? How will they feel about the research? How might that effect the results?

Research Dissemination Methods

- Create theater production/ play
- Presentations or seminars
- Flyers
- Social events
- Social media (Facebook, Twitter, etc.)
- Websites
- Poster presentation
- Information Table
- Resource Fair/ Health Fair
- Published paper
- Policy brief/ policy recommendation
- Word of mouth
- Press release
- Speaking with local politicians
- Interview with news media
- Meeting with advocacy group
- Teleconference
- Video

Financial Resources

The following section provides an overview of funding options and budgeting suggestions.

Funding Suggestions

Finding the funding for your project can be a great challenge. Applications for funding can take months and you may have to develop your idea before you can apply for the funding. However, don't allow this funding hurdle to stop your project. There are funding opportunities available and many projects can be implemented without funding or on a shoestring budget. The following sections provide information to guide your discussion about funding options.

Research on a Shoestring

Although you may not have much (or any) money, you can use other resources to get your project going. For example, the researcher or provider on your team may have access to office space for CBPR meetings and file storage. You can use volunteers or graduate students to help with data collection or analysis. Partner agencies may be able to provide incentives for participation in the research and meeting supplies (paper, coffee, etc.).

Pursuing Funding

Project costs may include compensation for study participants, payments to the CBPR team for their time working on the project and meeting supplies. Small grants are adequate for many CBPR projects and can be obtained more quickly through private organizations or individual donors. You will want to target potential donors that have an interest in your specific research topic. As the pursuit of funding can be a time-consuming process, we highly recommend designating one member of the leadership (perhaps along with a subcommittee) who is devoted to these efforts.

Grant Resources

21st Century Science Initiative
Ad Hoc Group for Medical Research Funding
Alexander von Humboldt Foundation
Alfred P. Sloan Foundation
Alzheimer's Association
American Association for Cancer Research
American Association of University Women
American Cancer Society
American Federation for Aging Research
American Foundation for AIDS Research
American Gastroenterological Association
American Heart Association
American Institute for Cancer Research
American Liver Foundation
American Lung Association
American Society for Microbiology
American Society of Clinical Oncology
American Society of Transplantation
Amyotropic Lateral Sclerosis Association
Aplastic Anemia Foundation
Arthritis Foundation
Awarded Grants
Bristol-Myers Squibb Company
Burroughs Wellcome Fund
Cancer Research Foundation of America
Cancer Research Fund of the Damon Runyon Walter-Winchell Foundation
Cancer Research Institute
Cancer Treatment Research Foundation
CancerNet Cancer Literature
CaP Cure (Prostate Cancer Foundation)
Career Development Awards
Carreras International Leukaemia Foundation
Catalogue of Federal Domestic Assistance
Center for Scientific Review
Centers for Disease Control and Prevention (CDC)
Code of Federal Regulations

Commerce Business Daily
Community of Science
Cystic Fibrosis Foundation
Damon Runyon Walter-Winchell Foundation
Department of Defense (DoD) / U.S. Army Medical Research and Materiel Command
Department of Energy (DOE) Office of Energy Research
Dermatology Foundation
Ellison Medical Foundation
Environmental Protection Agency
Epilepsy Foundation of America
eRA
European Molecular Biology Organization (EMBO)
Fanconi Anemia Research Fund, Inc.
Federal Register
FirstGov Reference Shelf
Fogarty International Center Programs
Foundation for Informed Medical Decision Making
Foundations On-Line
Friends of Jose Carreras International Leukemia Foundation, (US site)
Funding Opportunities and Notices
General Motors Cancer Research Foundation
Grants Policy and Guidance
GrantsNet
Helen Hay Whitney Foundation
Helen Hay Whitney Foundation
Hereditary Disease Foundation
Howard Hughes Medical Institute
http://www.aplastic.org/
Human Frontier Science Program
Immune Deficiency Foundation
Infectious Diseases Society of America
International Agency for Research on Cancer
International Myeloma Foundation
International Union Against Cancer
James S. McDonnell Foundation
Jane Coffin Childs Memorial Fund for Medical Research
Jane Coffin Childs Memorial Fund for Medical Research
Juvenile Diabetes Foundation International

Lady Tata Memorial Trust
Medical Research Council (of Canada)
Lauri Strauss Leukemia Foundation
Leukemia and Lymphoma Society of America
Leukemia Research Fund
Life Sciences Research Foundation
March of Dimes
Merck Genome Research Institute
Morris Animal Foundation
Multiple Myeloma Research Foundation
Muscular Dystrophy Association
National Cancer Institute
National Cancer Institute (NCI) Funding Opportunities
National Center for Research Resources
National Childhood Cancer Foundation
National Council of University Research Administrators (NCURA)
National Foundation for Infectious Diseases
National Heart, Lung and Blood Institute
National Institute of Allergy and Infectious Diseases
National Institute of Diabetes and Digestive and Kidney Disease
National Institute of General Medical Sciences
National Institutes of Health
National Institutes of Health Guide to Grants and Contracts
National Kidney Cancer Association
National Kidney Cancer Association
National Library of Medicine
National Marrow Donor Program
National Organization for Rare Disorders
National Science Foundation
NIAID Council News (National Institute of Allergy and Infectious Diseases)
NIH Applications and Forms
NIH ERA Commons
Office of Acquisition Management and Policy (OAMP)
Office of Extramural Research
Oncology Nursing Foundation
Patient Centered Outcomes Research Institute
Pediatric AIDS Foundation
Pew Charitable Trusts
Prostate Cancer Foundation

Research Research Lite
Rockefeller Brothers Fund
Ruth L. Kirschstein NRSA Research Training Grants and Fellowships
Scleroderma Foundation
Searle Scholars Program
Sidney Kimmel Foundation for Cancer Research
Society of Research Administrators (SRA)
The American Society of Hematology
The Arnold and Mabel Beckman Foundation
The Charles A. Dana Foundation
The Foundation Center
The FRAXA (Fragile X) Research Foundation
The Fulbright Program
The Gairdner Foundation
The Glenn Foundation for Medical Research
The International Life Sciences Institute
The Irvington Institute for Immunological Research
The Japan Society for the Promotion of Science
The Lymphoma Research Foundation
The Robert Wood Johnson Foundation
The Science and Technology Foundation of Japan
The Susan G. Komen Breast Cancer Foundation
The Whitaker Foundation
The World Health Organization
University of Washington Royalty Research Fund
Washington Technology Center
Whitehall Foundation
Wood Johnson Foundation
World Cancer Research Fund

These funding sources were compiled based in part on information from http://researchtoolkit.org.isomedia.net/index.php/developing-proposals/finding-funding

Other Funding Sources

- Kickstarter
- Crowdfunding
- Donors List Book
- Alderman Office
- Fundraising events
- City government
- Department of Public Health
- Agencies
- Foundations
- Private donors
- Hospitals
- Internal institutional grants

Budgeting Guidance

If you have funding for this project, this section provides guidance in budgeting that money. The leadership needs to have a detailed plan for how to spend money throughout the project to make sure that needed expenses will be covered. A sample budget template is provided in the Appendix. Most of the budget concerns should be addressed outside of the CBPR session among the group leaders. This is suggested so that valuable CBPR time is not spent discussing money concerns.

- The leadership will be responsible for outlining the budget and one leader will be responsible for tracking expenses. This individual should have a good understanding of financial responsibility. It is suggested that a system of checks and balances be implemented to avoid clerical errors and so that one individual does not become overwhelmed.
- One person is assigned to supply materials and necessities (such as coffee, snacks, pens, paper, etc.) for the CBPR session.
- Receipts should be kept and all expenditures should be recorded on the tracking spreadsheet.
- The leadership will meet quarterly to discuss budget concerns.
- Changes from the original budget usually need approval by the funding agency.
- Inform the CBPR about any concerns regarding the budget.

Compensation Process for CBPR Team Members

If there is funding for CBPR members, they must be paid in a fair and equitable way that is agreed upon by the leadership. Compensation is not only an incentive for group involvement, it is also important for increasing individual team members' sense of accomplishment. It is the responsibility of the leadership to make sure necessary funds are available at the time of each meeting. Leaders should be mindful about asking CBPR team members to complete assignments outside of group time and making sure any unpaid work is performed on a voluntary basis.

Compensation Process

- Leaders must inform members of any tax reporting requirements and have members complete necessary tax forms (ex- W-9 forms).
- Leaders must explain what CBPR members will be paid for and in what cases they would not be paid.
- When group members get compensation for their participation, they must sign a receipt that details the amount of compensation received and why it was given.
- The leadership is responsible for tracking attendance at each CBPR session.
- If gift cards are used, leaders must provide instructions for using the cards.

☐ If applicable, decide which member of the leadership will be responsible for compensating group members and outline your process for obtaining compensation.

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