

Community Based Participatory Action Research Partnership Protocol

Community Based Participatory Action Research (CBPAR) is a way of doing research in which community members and academic researchers are equal partners in all stages of the research process. This approach is also known as community-based participatory research (CBPR), participatory research (PR), and participatory action research (PAR). CBPAR has many benefits for both communities and for research itself, including:

- Increasing community trust in research
- Increasing likelihood that research results will lead to effective programs and products that communities want and can use
- Increasing validity of research results
- Creating connections between community organizations, clinics, and researchers that support partnerships and that share effective and relevant programs and products
- Increasing skills, connections, and opportunities for growth for all partners

Successful CBPAR projects depend on strong partnerships. Partnerships across organizations that have different goals, priorities, and access to resources are not always easy to build. The purpose of this document is to support partnerships to be ready and able to do CBPAR.

This document represents a joint effort between the SoLaHmo Partnership for Health & Wellness (SoLaHmo) at West Side Community Health Services, Inc. and the University of Minnesota's Program in Health Disparities Research (PHDR) Advisory Board gold standard sub-committee. SoLaHmo contributed key action steps and ethical considerations for partnership success from their "Partnership Protocol for Community Based Participatory Action Research (CBPAR)" document, and PHDR contributed in-depth information about key CBPAR principles that support successful partnerships. The content in this document is the result of varied perspectives from both community members and academicians.

This document may be used for a number of purposes by SoLaHmo members, PHDR staff, community partners, and research faculty as well as broader research communities, including:

- Sharing a set of expectations for how to collaborate that potential community and university partners can discuss early in the partnership
- Establishing a base for training individuals new to CBPAR
- Setting standards that may reduce disagreements or resolve conflicts between partners

This protocol has three sections:

1. The first section outlines key CBPAR principles that define how partners work together.
2. The second section provides a detailed description of each CBPAR principle and examples of ethical considerations that SoLaHmo has identified through multiple



research partnerships. These ethical principles are linked to the stages in the lifespan of a CBPAR research project, although each set of ethical considerations may be associated with more than one principle. Project lifespan stages are as follows:

- *PROJECT STAGE 1: Partnership Development*
 - Partnership Exploration Phase
 - Collaborative Planning Phase
 - *PROJECT STAGE 2: Implementation*
 - Early Implementation Phase
 - Recruitment/Data Collection Phase
 - Data Analysis Phase
 - *PROJECT STAGE 3: Dissemination/Next Steps*
 - Sharing Research Findings Phase (Community/Academic)
 - Planning Next Steps or End of Project Phase
3. The third section is a checklist for key steps in partnership building across the lifespan of a research project. This checklist can be used early in partnership development to make sure that all partners are on the same page in terms of expectations for how to collaborate at each step of the project. It can serve as a planning tool as the project moves forward.



Section 1: Community-Based Participatory Action Research (CBPAR)

Principles

1. Recognize that members of a community may have a shared identity that requires ethical protections in research
 2. Answer research questions that are important to the community, and that create solutions built on existing community strengths and resources
 3. Create pathways for the collaborative, equitable involvement of all partners in all phases of the research
 4. Create a balance between gaining knowledge and creating action for the benefit of all partners
 5. Empower partners to actively learn from each other and to pay attention to social inequalities
 6. Address how both social and environmental contexts affect health
 7. Share findings and knowledge gained with all partners and with communities, in a way that can be used to improve community health
 8. Involve long-term commitment by all partners
- References are listed on the reference page at the end of the document
 - Links to resources are listed at the end of the document



Section 2: Principles, Definitions, Best Practices, and Expectations

Principle 1: *Recognize that members of a community may have a shared identity that requires ethical protections in research*

It is important to emphasize that community members define “community.” Community may be a geographic area, a group of people with a common culture/ethnicity, or a network of people with shared interests and identity. Communities require ethical protections, as do individual research participants.

Activities and Action Steps:

- Engage in conversations in the community to understand historical research connections (how has academia worked with this community and/or organization before? What has the history of research looked like in this community?)
- Understand the community’s relationship with CBPAR
- Partners should listen carefully, interact respectfully, and be open to learning from each other.
- The community identifies how the research activities and findings could possibly be damaging to communities, and all partners work to prevent harm.
- Community researchers are “the face” of the research project in their own communities. As such, it is essential that the research project and its protocols are in line with core values of the community and community researchers. In order for community partners to maintain their integrity in the eyes of the community, community researchers should co-lead decisions related to processes of informed consent, recruitment strategies, research methods, language used to inform and engage community participants, how results are interpreted, and how findings are disseminated.

Community and Researcher Perspectives

“You have to be comfortable not knowing a lot. Learning to walk in a new community is like being a child. You need introduction and instruction. You need to learn your place and how much you don’t know”. –Academic Partner

Principle 2: *Answer research questions that are important to the community, and that create solutions built on existing community strengths and resources.*

Improved health can be most effectively addressed with community members at the research table as equal partners. Communities know the most important health needs that they struggle with. Communities also know their own strengths and how those may be used to address the problem. Working with



communities to identify problems and build on existing strengths is likely to produce the most valid research results and effective action programs based on the research results.

Activities and Action Steps:

- Establish accountable relationships among community leaders, community members and academic researchers before trying to intervene, address problems, or bring up possible solutions.
- Identify community strengths and resources and identify systemic challenges through conversations with community leaders, discussions in community forums, or formal assets assessments
 - Resource: Community Tool Box, Chapter 3, Section 8: Identifying Community Assets and Resources
 - Resource: Community Assets Brainstorming Activity (County Health Rankings & Roadmaps, 2013).
 - Resource: Asset-Based Community Development Toolkit (ABCDI, 2015)
- Ensure that the research is tailored to the specific community desires
- Utilize collaboration and engagement to support the development of the research process, which includes identifying research questions that reflect issues of community interests.
 - Resource: Concept Mapping as an Approach to Facilitate Participatory Intervention Building (Allen, Schaleben- Boateng, Hang, &Pergament, 2015).

Community and Researcher Perspectives

“Everyone was aware of the strong added value that this [CBPR project] was bringing to the community. When you are doing research for things that are really meaningful for the community you get the sustainability, the extra support.” – Community Partner

Principle 3: Create pathways for the collaborative, equitable involvement of all partners in all phases of the research

Projects are most likely to be successful when community members are involved from the very beginning of planning a study through the end of the project. Many communities have been asked to join research projects after the topics, questions, intervention, and implementation plans have already been decided. Sometimes these may fit well with community interests, but often communities have other priorities.

Activities and Action Steps:

- Develop or make use of documents that build partnership synergy, such as:



- Tools to support early conversations about partnership processes, such as the Partnership Checklist. The Checklist is a series of questions that help partners talk through key partnership issues early in their relationship.
 - Resource: See references page for link
- Memorandum of Understanding or Collaborative Agreement. These are partnership agreements that can change over time, as needed. They outline how partners will work together across the lifetime of the project. They address key aspects of collaboration such as communication, decision making processes, and sharing research findings (dissemination).
 - Resource: Memorandum of Understanding Template (UMNOPE, 2016)
- Mission statement. Establishing a mission statement is a way to define common goals and priorities.
- Data sharing and authorship agreement. This document formalizes who owns the data, who has access to the data, and who will be authors on future journal articles (for example, are community partners listed as authors on all publications, do they need to approve a final publication?).
- Establish group processes including:
 - Honest and frequent communication through agreed upon channels
 - Established roles and responsibilities
 - Equal representation for community and academic partners in all aspects of the work, including naming community researchers co- principal investigators or co-investigators in journal articles.
 - Decision making process that all partners have agreed upon (consensus, voting, etc.)
 - Openness about each partner’s priorities and needs, as well as organizational culture and potential barriers.
- Co-develop a budget
- Participate in partnership evaluation to understand how well the partnership is progressing and meeting its goals.

Community and Researcher Perspectives

“It’s important to talk about the money. The university is going to take their percentage. Put that stuff upfront.” – Community Partner

“I think the other piece is with having community partners on board. From very early on, what are the benefits to the community? They need to be articulated”. – Academic Partner



Principle 4: Create a balance between gaining knowledge and creating action for the benefit of all partners

CBPAR projects should identify community-oriented dissemination strategies, from early action steps of importance to communities to disseminating final results. Research is a slow process that may require years to produce results. Researchers may be accepting of this while communities may experience frustration, given their sense of urgent priorities that demand action. Early action steps made before final research outcomes are available can address this concern.

Research results need to be shared in ways that both community members and academicians can understand. When the community does not hear about the findings, does not have access to the findings, or does not understand the language in which the findings are shared, then the community cannot make use of the results and academic partners take away the knowledge for their own benefits. Clear agreements should be established early regarding dissemination strategies, ownership of data, location of raw data and analyses, and how all partners will have access to the data overtime and as new priorities or uses emerge.

Activities and Action Steps:

- An MOU/collaborative agreement should address dissemination plans for early and late outcomes to both community and academic audiences.
- Establish an early plan for action steps such as community dialogues, presentations to community boards, or opportunities for select organizations to use early results in a program.
- Make sure that the budget addresses the resources that will be needed for dissemination and for sharing findings at community events, including language translation/interpretation, food and child care transportation costs.
- Create a process that allows for community evaluation about the dissemination processes.

Community and Researcher Perspectives

“We need more transparency. We need to put it on the table. People never talk about that they have to write papers. They need to get tenure. Let’s be up front and tell people why we’re doing what we’re doing”. – Community Partner

“The community leaders and members think the research topic is relevant and worth discovering. With both researchers and community leaders and members coming together to do the research, the hope is to create services that will benefit the community someday down the road”.- Community Partner



“I think it would be important to share with the community how academicians have to balance their own needs for promotion and what I call the “bean counting” that we are forced to do as faculty, with the realities of doing (CBPR) research. Again, if the community members haven’t been part of the academic world, they likely will not know what benchmarks we have to meet for our own careers”. – Academic Partner

Principle 5: Empower partners to actively learn from each other and to pay attention to social inequalities

Our society tends to legitimize the perspectives of certain people over others based on age, race, ethnicity, gender identity, sexual orientation, education level, and socio-economic status. CBPAR works to create institutional change and promote actions to address social inequalities through building meaningful and collaborative processes, discovering valid truths and perspectives, and using the insights to redress health inequities.

Activities and Action Steps:

- Growing in cultural understanding allows partners to acknowledge their key differences and similarities. Partners value differences across cultures, ages, gender identities, institutional affiliations, abilities, education, socio-economic and other differences.
- Rely on community knowledge and expertise to establish roles, rules, and group processes that support all partners’ participation in creating meaningful, lasting action.
- Rely on community knowledge and expertise to establish meaningful, clear language so that research participants will understand the purpose of the research project and what their role is, and will feel that they and their community are respected in the process.
- Bring community perspectives and knowledge into: designing surveys, participatory data analysis and interpretation
- Participate in partnership evaluation.
- Have a process to explore experiences and perspectives when disagreements or conflicts arise.
 - Resource: Dispute Resolution Center
 - Resource: University of Washington CBPR Partnership Curriculum, Unit 4, Section 4.5: Resolving Conflict



Community and Researcher Perspectives

“The native community can easily be so skirted around because of research and it is important to have conversations around developing trust when community in general has a big amount of distrust, due to many factors, including research that has previously been conducted in the community”- Community Partner

Principle 6: Address how both social and environmental contexts affect health

Communities may suffer from stigma by research that focuses on individual behaviors apart from the broader social and environmental forces that contribute to those behaviors. When research projects focus primarily on individual behaviors, the limited results lead to limited potential solutions.

Activities and Action Steps:

- Identify the social, cultural, historical, and political factors that affect the health issue being studied.
- Consider how these factors can change the response to the health topic being measured.
- Consider how these factors influence the research topic and results.
- Consider how these factors affect how the research results are presented. For example, communications director UMN General Pediatrics and Adolescent Health, Glynis Shea, encourages researchers to consider the messages that are being shared around health disparities. These messages may act as a barrier to public support because they focus on the individual rather than the broader social and environmental forces that lead to individual behavior.
 - Resource: Health Disparities Presentation by Glynis Shea
 - Resource: Health Disparities and Pediatrics Messaging Presentation by Glynis Shea

Community and Researcher Perspectives

“To truly understand the context contributing to behaviors you have to be working in partnership with the people experiencing those behaviors”. –Community Partner

“SoLaHmo recognizes that community-based research does not happen in a vacuum. Rather, it takes place within the context of historical and current social injustices. Throughout history, research has been used to stigmatize, racialize and disempower communities of color and other marginalized groups. SoLaHmo seeks partners who recognize this and who want to engage with us to utilize a CBPAR



approach as a tool to advance community agency and self-determination in health equity.”- SoLaHmo Executive Committee

Principle 7: Share findings and knowledge gained with all partners in a way that can be used to improve community health.

CBPAR knowledge production is built on a strong collaboration that assumes community access to and ownership of data. The research results need to be shared equitably in ways that both community members and academics can understand. When the community hears about and has access to the findings, and understands the language in which the findings are shared, then they can make effective use of the results and share in the benefits of the research.

Activities and Action Steps:

- A MOU/collaborative agreement should outline location of raw and analyzed data. Will it reside at a community site with University researcher access? Will it reside at the University, and if so how will community have access to the data over the short term and long term? How will data security be maintained?
- Define together what equitable sharing looks like. How should research results be presented so that the community can understand and make use of them?
- Ensure that the results are presented to both the community and academic audiences. This should have been addressed in the MOU and data sharing agreements.

Principle 8: Involves long-term commitment by all partners

Many communities have experienced that academic researchers may enter and leave a community as funding varies, regardless of whether or not community goals have been met. In CBPAR, partners commit to a set of common goals with the expectation that every effort will be made to find funding to reach those goals.

Activities and Action Steps:

- Sustainability should be considered at the onset of a project
 - Partners should always ask, what will happen when this project ends? What is the plan for community to hold the change that has happened?



- Commitment should be made to seek long term funding

Community and Researcher Perspectives

“Some of this work takes time. You are not going to get it done overnight. You need to have the long term commitment in mind”. – Community Partner

“Administrators need to recognize that we can’t go into community in an uncommitted way. We have to be there for the long term and the project may morph. You have to dive into the river and swim where the river takes you”. – Academic Partner

“The big motivator of this [CBPR] project is the need of the community. I was aware of the need, but we did not have the capacity, and I did not trust the university. The distrust was bigger than the need at that moment. In my mind: Yeah great, but they are going to do what? As always they do research, and then fly and go away, and we will have the same issue in three years, when the project is done. What’s the point?” – Community Partner



Section 3: SoLaHmo's Partnership Action Steps Along a Project Stages Timeline

Note: Some stages are overlapping and repetitive so that there is flexibility in the stages.

PROJECT STAGE 1: PARTNERSHIP DEVELOPMENT

1. Partnership Exploration Phase

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| CBPAR Principles: 3,5,7 & 8 |
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- 1-3 meetings to discuss topic and potential partnership*
- Determine if all partners are interested in the topic and CBPAR process. Is there a fit?
- Present SoLaHmo decision-making process (typically Consensus)
- Identify research questions and methods together
- Identify grant opportunities
- Attend to ethical considerations:
 - ✓ Are community researchers Co-Investigators (Co-I's)/Co-Principal Investigators (Co-PI's)?
 - ✓ Are SoLaHmo/community members represented at project leadership level?
 - ✓ Have there been discussions about how knowledge production will **benefit community** and advance community health?
 - ✓ Have there been discussions about how to frame the health topic within social, cultural, historical and political contexts?
 - ✓ Is the partnership using SoLaHmo Cultural Asset Framework?

2. Collaborative Planning Phase

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| CBPAR Principle: 3 |
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- Decision to move forward together has been made
- 1-2 initial meetings to develop specific ideas for proposal*
- Develop an initial collaborative agreement with Co-PI's and others as time permits (Project Goals, Decision-Making, Communication, Accountability, Data Access and Use, Conflict, Data Ownership, Dissemination of results, Sustainability)
- Write grant/s
- Develop budget/s: (consider: 6-8 hours for collaborative agreement; translation, transcription, travel, meeting costs with food, participant costs, including childcare and transportation)
- Develop timeline/s
- Complete IRB application when needed (i.e., federal grants)
- Discuss SoLaHmo translation protocol (or one that ensures meaning-for-meaning translation, as opposed to word-for-word translation of your documents and tools), Community Advisory Board processes, and participatory analysis process

- Build time into budget for partnership planning/partnership evaluation
- Attend to ethical considerations
 - ✓ Are community researchers Co-I's/Co-PI's?



- ✓ Does the project budget include funds for research participant childcare, transportation, and food?
- ✓ Does budget include funds for community dissemination, including translation of dissemination materials?

PROJECT STAGE 2: IMPLEMENTATION

1. Early Implementation Phase

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| CBPAR Principles: 2 & 7 |
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- Secure funding
- Form team/s. Discuss individual expectations, reasons for being at the table, and personal assets.
- Develop Collaborative Agreement *over 3-4 two-hour meetings*: Project Goals, Decision-Making, Communication, Accountability, Data Access and Use, Conflict, Data Ownership, Dissemination of results, Sustainability
- Develop other partnership elements
- Review timeline and deliverables and revise if necessary
- Complete IRB application in collaborative manner. Consider protections for SoLaHmo researcher integrity in own communities, prevent individual & community harm.
- Complete appropriate trainings for academic partners and new SoLaHmo researchers (CBPAR; Optional: SoLaHmo's Community Research Ethics)
- Develop research tools collaboratively (consent forms, recruitment scripts/letters, surveys, interview questions, etc.)
- Develop research methods collaboratively (consider delayed interventions for pilot studies)
- Finalize recruitment strategy
- Discuss dissemination strategy (consider phasing over life of project instead of just at the end)
- Attend to ethical considerations:
 - ✓ Is the partnership applying cultural lens and literacy considerations when developing documents, methods, tools, etc?
 - ✓ Is the partnership utilizing SoLaHmo's translation protocol (or one that ensures meaning-for-meaning translation, as opposed to word-for-word translation to your documents and tools)?
 - ✓ Are SoLaHmo/community partners part of the application and IRB process? Are SoLaHmo/community partners' and organization's integrity being protected or being considered? Is the partnership considering how to prevent both individual and community harm?
 - ✓ Is the partnership using SoLaHmo community/cultural asset framework?

2. Recruitment/Data Collection Phase

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| CBPAR Principles: 1, 3, 5, 7, 8 & 9 %& |
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- Conduct: Recruitment, Consent, Data Collection

- Mange data (data entry, transcription/translation)
- Attend to ethical considerations



- ✓ Is the partnership applying SoLaHmo cultural asset framework in coding and interpretation
- ✓ Is the partnership taking steps to prevent contributing to current or possible stigma in data interpretation?
- ✓ Are partnership members aware of personal and professional preferences, assumptions, and biases? And has the partnership team discussed these when they arise?

3. Data Analysis/Interpretation Phase

CBPAR Principles: 1, 3, 4 & 6

- Complete participatory analysis training
- Conduct participatory analysis
- Attend to ethical considerations
 - ✓ Is participatory analysis happening so that community partners are involved in each relevant aspect of analysis and interpretation?
 - ✓ Is the partnership discussing the CBPAR process with the entire team and how, when, and where findings will be shared?
 - ✓ Have you discussed how to present findings in a way doesn't reflect negatively on, or create stigma for, the communities that participated in the study?

PROJECT STAGE 3: SHARING RESEARCH FINDINGS & PLANNING NEXT STEPS

1. Sharing Research Findings Phase (Findings shared equitably with community & academic audiences)

CBPAR Principles: 3 & 7

- Share research findings with community members
- Share research findings with academic audiences
- Attend to ethical considerations
 - ✓ Is the partnership discussing the CBPAR process with the entire team and how, when, and where findings will be shared?
 - ✓ Is the partnership considering and discussing about how to present findings in a way that prevents community stigmatization?
 - ✓ Is the partnership developing parallel processes for community & academic dissemination (make community dissemination a priority)?
 - ✓ Are community researchers co-authors/co-presenters on both community and academic dissemination efforts?

2. Planning Next Steps or End of Project Phase

CBPAR Principles: 2, 3, 4, 6, 8 & 9



- Write reports
- Prepare for ongoing dissemination
- Identify next steps (New grants, New goals/methods identified, etc)
- Write further grants
- Attend to ethical considerations
 - ✓ Do next steps reflect both community researcher and academic researcher priorities and interpretations?



References and Resources

References Section 1

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References Section 2

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Resources Principle 2:

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Resources Principle 3:

*Partnership Checklist link:

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Resources Principle 5:

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Resources Principle 6:

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<https://www.youtube.com/watch?v=-EvhWx45Ei8>

- Corresponding PPT slides:

<https://drive.google.com/file/d/0B7ZA9EbqndaoX1h6WIZZQjFYV3M/edit>

