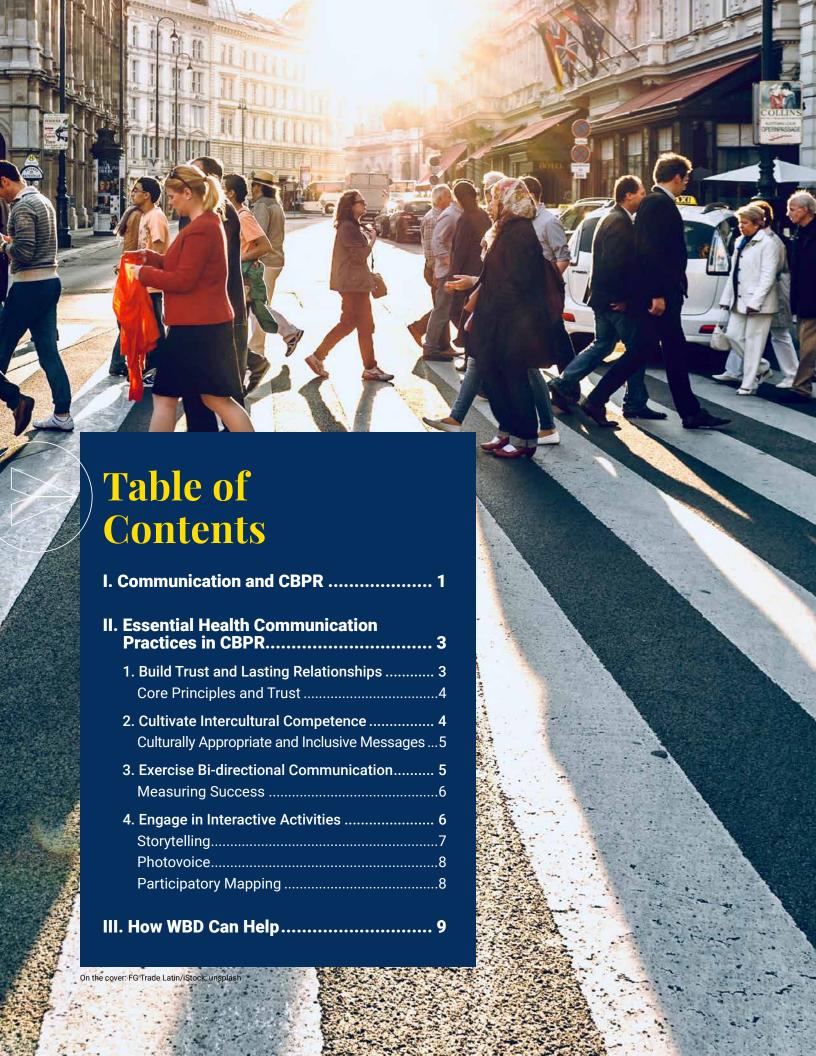




By Mary Jane Maxwell, Ph.D.



I. Communication and CBPR

Community-based participatory research (CBPR) is a research approach that involves collaboration between researchers and community members to identify research questions, design and conduct studies, and translate findings into actions that benefit the community. Scientists, academic researchers, public health professionals, and community leaders increasingly rely on CBPR to address health conditions that **disproportionately affect groups that have been economically and socially marginalized.** The CBPR approach acknowledges the importance of cultural context, historical factors, and community expertise in addressing complex health issues and promoting social change.

The evolution of CBPR dates to the civil rights and social justice movements of the 1960s and 1970s. As a research method, participatory action research strengthened in the 1970s by listening to groups that had been marginalized and addressing the concerns that mattered the

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emerged with the recognition of health disparities and the social determinants of health in the 1980s and 1990s. The participatory approach also responded to historic research abuse (e.g., physical harm, cultural misrepresentations, and research results not returned to the community or used for their benefit) committed on American Indians, Alaskan Natives, and African Americans.³ Community-based participatory research continues to evolve, and the health community considers CBPR's equal partnership approach the best means to improve health conditions and reduce diseases that disproportionately affect populations with health disparities.

CBPR is preferred over traditional research methods because traditional research designs lack community input and knowledge. This absence has often produced disconnected findings from real-world community contexts, making it challenging to address community health issues. For example, in a traditional research scenario, scientists might enter a community with pre-determined questions to advance their funded breast cancer research. However, the community wants and needs information and resources to reduce the high diabetes rates among its population.

CBPR represents a paradigm shift from traditional research methods by placing communities at the center of the research process. Rather than focusing on a funded research topic, the purpose of the research switches to addressing the community's needs and when they need it. The important research questions stem from what will benefit the community rather than how it will advance a research agenda.

Difference Between Traditional Research Methods and CBPR

Traditional Research Methods

Researcher-Centric: Traditional research methods are often researcher-driven, with researchers identifying research questions, designing studies, and implementing data collection and analysis without substantial input from the community.

Focus on Objectivity: Traditional research aims for objectivity and generalizability. Researchers strive to minimize biases and control variables to isolate specific factors being studied.

Emphasis on Controlled Settings: Controlled environments and standardized procedures are common in traditional research to ensure consistency and reduce confounding variables.

Limited Community Involvement: Communities may serve as research subjects or participants in traditional research, but their involvement in shaping research questions, designing studies, and interpreting results is often limited.

Potential for Disconnected Findings: Traditional research may produce findings that are disconnected from real-world community contexts, making it challenging to apply the results effectively to address community issues.

Community-Based Participatory Research (CBPR)

Community-Centric: CBPR is community-driven, involving collaboration between researchers and community members from the outset. Communities actively participate in defining research questions, designing studies, and implementing interventions.

Focus on Equity and Empowerment: CBPR aims to address health disparities, promote equity, and empower marginalized communities by involving them in decision-making and problem-solving processes.

Emphasis on Real-World Context: CBPR often takes place in natural community settings, allowing researchers to better understand the contextual factors that influence health and well-being.

High Level of Community Involvement: Community members are considered equal partners in CBPR projects. They contribute their expertise, experiences, and local knowledge to shape research, implementation, and interpretation.

Action-Oriented and Sustainable: CBPR seeks to translate research findings into meaningful actions that benefit the community. Interventions are designed with community needs and preferences in mind, increasing the likelihood of sustainability.

Long-Term Relationships: CBPR projects often involve long-term relationships between researchers and communities, built on trust and mutual respect.

Ethical Considerations: CBPR places a strong emphasis on ethical considerations, including informed consent, cultural sensitivity, and respect for community values.

Co-Learning: Researchers and community members learn from each other, bridging academic knowledge and local wisdom to create more relevant and impactful research.

Process-Oriented: CBPR places value on the process of collaboration itself, recognizing that building strong partnerships and engaging in open dialogues can contribute to positive outcomes beyond research results.

At its core, CBPR is **a two-way dialogue** between researchers and community members (members also referred to as partners or participants). While CBPR begins with a research topic, its goals are to translate the research findings into action — tailored interventions or a public health campaign — to improve health outcomes and eliminate health disparities.⁵

Because communication between researchers and community members underlies every aspect

of the CBPR approach, researchers must cultivate the best health communication skills and practices to achieve the best health outcomes. The most effective communication in CBPR goes beyond transmitting information; it fosters collaboration, empowerment, and shared decision-making between researchers and community members. As these relationships evolve and deepen, new research topics emerge, and future studies find a receptive pool of partners and

II. Essential Health Communication Practices in CBPR

participants.

1.Build Trust and Lasting Relationships

Authentic, long-term CBPR partnerships begin well before researchers approach a community seeking participants for a project. Community partnerships take time, effort, and resources to establish. To ensure ongoing collaboration, researchers must prioritize building relationships with community and ethnic leaders, traditional and local authorities, influential community residents, local organizations, and citizen activists. Rather than approach community organizers with a grant already in mind, researchers must take time to build an equal partnership long before discussing research projects.

Establishing trust involves acknowledging community members' expertise and engaging

Partnerships between universities and their local community(s) comprise many CBPR projects. For example:

- Johns Hopkins University maintains wellestablished relationships with community leaders and organizations throughout Baltimore.
- Morgan State University, also in Baltimore, has intentionally used the CBPR approach with its community partners for two decades.
- ➤ Funded by the National Institutes of Health (NIH), the <u>CBPR Partnership Academy</u> at the Detroit Urban Resource Center offers training for new academic-community partnerships.

community members at all stages of the research process. Researchers need to learn as much about the community as possible, adopting a **mindset of serving rather than studying** a group or groups. Building trust develops from consistent communication, such as regular listening sessions with a complete representation of community members.

Transparency in the research process is also crucial to building trust. This means **communicating clear and accessible information** regarding the research goals, methods, and findings to community members promptly and appropriately. When academic researchers prioritize transparency, the community receives the knowledge required to hold researchers accountable and ensure that research initiatives are equitable and socially responsible.

Here are some essential communication principles and practices for researchers to develop to build trust and strong relationships with their community partners.

- Recognize and value the expertise that community members bring to the research process.
- Maintain trust by respecting each other and remaining honest and transparent about all aspects of the research.
- Welcome and address differing views among partners.
- Hold meetings in locations that are easily accessible and convenient for the community's residents (i.e., not at the university.)

Most of all, listen more and talk less; remember, the community members are the experts on their needs and the existing barriers.⁷

Core Principles and Trust

Scientists and community leaders adhere to a framework of common principles throughout a CBPR project. These frameworks emphasize establishing trust between academic researchers and community members through transparent, bi-directional communication. Two common frameworks are the Centers for Disease Control and Prevention's (CDC) Principles of Community Engagement and the National Academy of Medicine's CBPR conceptual model and Core Principles of Community Engagement. Although these principles exist, CBPR academics and practitioners must hone the appropriate health communication skills necessary to practice these principles and foster respect and trust.8

Core Principles of Community Engagement from the National Academy of Medicine

The core principles identify attributes that are foundational to the process of community engagement. Those involved must ensure that community engagement is grounded in trust, designed for bi-directional influence and information flow between the community and partners, inclusive, and premised on culturallycentered approaches. The core principles also include equitable financing, multi-knowledge, shared governance, and ongoing relationships that continue beyond the project timeframe and that are authentic and enduring. Engagement should be co-created and participants should be considered co-equal. Principle-informed community engagement creates a readiness that can propel teams into productive motion and accelerate engagement outcomes and the ultimate goal of health equity and systems transformation.

2. Cultivate Intercultural Competence

Intercultural competence means considering the diverse backgrounds of community members and perspectives while developing and implementing research strategies. Researchers must acknowledge the history and context of intercultural experiences in a community and ensure that research methodologies are respectful, ethical, and culturally appropriate. Where pertinent, academics and scientists should acknowledge structural racism and historical neglect and abuse in a community.⁹

Effective and appropriate communication with a community that has been socially and economically marginalized requires training in cultural humility. A good resource includes the Center for Cultural Humility at Cornell University, which offers evidence-based cultural engagement training for researchers, clinicians, and administrators.¹⁰

Culturally Appropriate and Inclusive Messages

The best communication messages signal to the entire community that **all members belong here.** Here are some essential communication practices to ensure inclusivity.

- Hire local staff and include partners in preparing all communication materials.
- Display culturally appropriate language(s), visuals, and examples that resonate with the community's cultural background and values.
- Present information in clear, concise language without jargon or technical terms.
- Use a variety of formats such as written,

- audio, video, and braille to ensure the information is available and accessible for all community members with different learning styles and literacy proficiency.
- Consider local idioms, symbols, and traditions to enhance understanding and engagement.
- Offer a mix of communication channels such as community meetings, social media, local newspapers, radio, and community health workers.

If faculty members, physicians, or researchers are also members of the community and speak similar languages, invite them to facilitate meetings and listening sessions. If community members speak more than one language, make sure all written and oral communication reflects all languages — bilingual and, if necessary, trilingual. Encourage other participating organizations to do the same.

3. Exercise Bi-directional Communication

Bi-directional communication is a fundamental principle of CBPR, emphasizing the reciprocal exchange of information and knowledge between researchers and their community partners. This approach ensures that both parties learn from each other and contributes to a more equitable and effective research process. Opportunities for bi-directional communication exist at every stage of the research process and are not limited to focus groups and identifying research questions.

Here are several practices to ensure bi-directional communication takes place at every step in the research process.

- Provide regular and ongoing opportunities for partners to share their knowledge and experiences, and voice health concerns from their perspective.
- Listen actively to community members' perspectives, concerns, and insights and incorporate their input into the research questions, study designs, and interventions.
- Create a feedback loop for all participants to ask questions and voice their concerns and respond promptly.
- Provide resources directly to the community to build capacity among locals, such as citizen scientists or community research teams and advisory boards.
- Incorporate community members' input in shaping research questions, study design, and interventions.
- Collaborate to analyze research data by sharing findings, interpretations, and reflections to collectively make sense of the data.

By establishing regular focus groups and meetings, researchers and community members can share their perspectives, experiences, and ideas about health and community priorities. This bi-directional exchange of information helps refine research questions, design data collection methods, and ensure that research findings are accurate and relevant.

Researchers should also facilitate workshops and provide training on research methods, data collection, and data analysis with community members. Building capacity among residents "Still, a focus group itself does not transform academic-community relationships if academics are making all the research decisions. A fully participatory approach requires a structured mechanism, such as community advisory boards, community research teams, or community scientific research committees, so that academic researchers can work in ongoing partnerships with other stakeholders." 11

Nina Wallerstein Commentary on Community-Based Participatory Research and Community
 Engaged Research in Health for Journal of
 Participatory Research Methods. Journal of
 Participatory Research Methods. 2020;1(1).

actively engaged in the research process is essential to creating and maintaining an equal partnership. Simultaneously, community members can provide insights into local contexts, cultural nuances, and community priorities to help co-create survey questions and interpret data in its fullest context.

Measuring Success

Co-learning, one of the principles of CBPR and a consequence of bi-directional communication, empowers communities to take charge of their health issues, guide the direction of the research

from their perspectives, and focus on the community's strengths. ¹² Publishing research results in an academic journal is not the only measure of success. The best measure of CBPR's success in reducing health disparities is when the community partner takes ownership of the research findings, communicates results in their language (where appropriate), and disseminates them via local publications.

4. Engage in Interactive Activities

Interactive activities play a crucial communication role in CBPR because they foster engagement, co-learning, and empowerment among all partners and participants. Specific CBPR interactive activities that have emerged from academic-community partnerships include storytelling, photovoice, and participatory mapping approaches. These actions engage community members as active partners in the research process, ensuring that the research is grounded in local contexts and addresses real community needs. A literature review reveals that participatory artsbased and other innovative approaches are increasingly recognized in CBPR scholarship. 14

Storytelling

Researchers, public health officials, and community organizers are increasingly incorporating non-Western means of knowing, conducting research, and communicating data and results in CBPR projects. For millennia, indigenous cultures relied on storytelling to produce and transmit knowledge. Storytelling as a communication

"Incorporating Native traditions of storytelling and artistic expression into research methods and community interventions is a means of focusing on the importance of traditional modes of connectedness or culture.

Doing so may boost the impact of health promotion programs because identification with one's culture and enculturation have been associated with resilience and health."

- Gray N, Oré de Boehm C, Farnsworth A, Wolf D. Integration of creative expression into community-based participatory research and health promotion with Native Americans. Fam Community Health. 2010 Jul-Sep;33(3)

tool can advance health outcomes in Indigenous communities.¹⁵ As a health research method, storytelling is a means to decolonize health research on Indigenous peoples by acknowledging it as a valid system of knowledge equal to Western scientific methods.¹⁶

Over the past few decades, Western medical practitioners have employed storytelling as an effective means of collecting healthcare data and analysis.¹⁷ A recent scoping review of storytelling methods in Indigenous health research,

conducted by Indigenous and non-Indigenous researchers, offered critical findings, or "respectful ways," that researchers use storytelling in Indigenous health research.¹⁸ Based on that review, here are several best storytelling practices:

- Receive mentorship or training from Indigenous peoples in culturally appropriate research methods. For example, one researcher received training in the "art of listening" from Elders.
- Find a facilitator, an Elder or Indigenous community member, with awareness of barriers to storytelling and create a safe space for community members to share their stories.
- Honor and privilege Indigenous languages in storytelling by asking participants to use the language they prefer. Translate stories or phrases told in Indigenous languages into English.
- Determine and incorporate appropriate cultural protocols in storytelling. Some protocols discussed included spiritual ceremonial practices before and after a story, smudging with traditional medicines (e.g., sage), feasts, and sweat lodge ceremonies.

Storytelling is a powerful communication tool because it allows community members with various literacy skills to articulate their concerns and knowledge to researchers. Stories can evoke empathy, engage listeners emotionally, and bridge the gap between communities and researchers. Particularly in CBPR, where the goal is to create an equitable and collaborative research process, storytelling allows for the co-creation of knowledge, empowering community members to actively participate in decision-making and policy formulation.

Photovoice

Photovoice is a participatory research method that combines photography and storytelling, enabling community members to express their perspectives and experiences on a specific topic.

Caroline Wang and Mary Ann Burris developed the method in the 1990s to empower communities to document their lived realities and advocate for positive social change.²⁰ Photovoice involves participants taking photographs to communicate their viewpoints and then using those images to engage in discussions, storytelling, and dialogue within the community and with researchers.

In CBPR, photovoice is an effective communication activity for democratizing the research process because it allows community members to actively contribute to research design, data collection, and interpretation.²¹ Their participation helps to ensure the research is community-driven and responsive to their needs and priorities.

Benefits of photovoice include:

Visual Data Collection: Through photovoice, participants become active researchers, capturing visual data beyond traditional text-based information. The photographs provide a unique and intimate insight into the participants' daily lives, challenges, and experiences.

Community Dialogue: Photovoice encourages community members to dialogue with each other and researchers. Group discussions, workshops, and community exhibitions of the photographs foster conversations about the issues depicted and the broader implications for the community.

Collaborative Research: Researchers work closely with partners to select themes, analyze the images, and discuss findings. This collaborative approach ensures that community priorities and needs drive the research.

Participatory Mapping

In participatory mapping, participants contribute to maps in response to a research question. The exercise acknowledges how the built environment affects its residents' health behavior and outcomes, and failing to include the physical context of where community members live, work, and play could diminish the research analysis and subsequent interventions.22 This interactive activity is a potent CBPR communication tool because it engages community members, represents local knowledge, and facilitates collaborative dialogue. Because the map brings a visual and spatial dimension to CBPR, the participatory mapping method offers a critical perspective in highlighting community assets and identifying needs.23

Participatory mapping also provides additional means for more community members to actively engage in data collection and analysis. The maps serve as a visual language that transcends literacy and language barriers, ensuring that information is accessible to a broader audience.

Community Engagement: Participatory mapping engages community members actively in the research process. Researchers encourage dialogue and collective exploration of the community's concerns, priorities, and assets by involving them in mapping workshops or activities. This hands-on approach fosters a sense of ownership

"Mapping approaches can help participants and researchers to see and use data differently, and to access types of data that may otherwise remain hidden, including perceptions, emotions and experiences."

Dr. Deborah Ralls, University of Manchester

and investment in the research, enhancing community members' willingness to engage in further discussions and collaboration.

Shared Knowledge: Participatory mapping provides a platform for sharing local knowledge, experiences, and insights. It is also helpful for integrating Indigenous and Western knowledge systems.²⁴ These shared insights enrich the accuracy and relevance of data by offering perspectives that traditional data collection methods might not capture.

Visual Language: Participatory mapping transforms complex information into easily understandable visual representations that facilitate communication, engagement, and collaboration in CBPR. This visual language helps overcome literacy and language barriers, ensuring all community voices are heard and acknowledged.

Participatory mapping can improve accuracy, promote equity, and enhance the relevance of research outcomes.

III. How WBD Can Help

Community-based participatory research presents unique challenges for community organizations and researchers. The CBPR approach is time and resource-intensive because it involves building relationships with community members and collaboratively conducting research.

WBD can provide valuable support to a community-based participatory research project. Our expertise in health communication, project management, data collection and analysis, strategic planning, capacity building, and evaluation can enhance the overall effectiveness and success of the CBPR project. By collaborating with WBD, research teams can benefit from additional resources and expertise, ensuring that the research process and outcomes align with community needs and aspirations.

Here are a few ways that WBD can support an academic-community partnership engaging in CBPR.

Health Communication

The health communication experts at WBD can collaborate with community members and researchers to design communication plans that ensure clear and culturally appropriate messaging. Our health communication experts and science writers support our clients at the Veterans Health Administration and the National Institutes of Health. We assist in developing information and material in accessible formats that diverse audiences can easily understand.

Our experts understand the importance of engaging diverse community members in research projects and can help create spaces for open and transparent communication, encourage active participation, and address any concerns or barriers that may arise. Because of our expertise in strategic planning and stakeholder engagement, our consultants can assist in facilitating meetings and workshops that foster collaboration and shared decision-making.

For our client at the Veterans Health Administration, WBD's team of health communication experts provide full communications and creative support to VHA's Office of Healthcare Innovation and Learning (OHIL) and VHA's Innovation Ecosystem. In 2023, our health communication consultants won recognition for our client via awards and news coverage while elevating the messages and initiatives designed to support U.S. veterans.

Data Collection and Analysis

Our data analytic team can assist in designing data collection tools, such as surveys or interview protocols, and guide data collection techniques. In addition, our team can help process and analyze the collected data using appropriate statistical or qualitative analysis methods. We are proud to support our U.S. Department of Defense client with our innovative data technologies, and we can help identify key findings and trends to help inform CBPR outcomes.

Capacity Building

WBD has long supported our federal clients with capacity building efforts in diverse international and domestic communities. Our skilled consultants can provide training and workshops on research methodologies, data collection and

analysis, and project management. This learning can help community members build their skills and knowledge, ultimately empowering them to take a more active and informed role in the CBPR project. By equipping community members with the tools and resources they need, our consultants can help create sustainable research practices within the community.

Evaluation and Impact Assessment

WBD can assist in evaluating the outcomes and impacts of CBPR projects. Our consultants have developed evaluation frameworks and conducted assessments to measure the effectiveness and success of research projects for the U.S. Agency of International Development, the Millennium Challenge Corporation, and the U.S. Department of Commerce. By assessing CBPR outcomes, we can provide recommendations for improvement and identify best practices for future CBPR initiatives.

Project Management

With decades of expertise in project management methodologies, including our federal client at the Federal Emergency Management Agency (FEMA), WBD's consultants can provide valuable guidance in planning, organizing, and executing CBPR projects that align with CBPR principles. Our knowledge of project management tools and techniques can enhance the overall effectiveness and success of the CBPR project.

Budget and Funding

WBD can assist with identifying funding opportunities and developing grant proposals to support

CBPR projects. Our financial analysts and budget specialists are proud to help our clients at the DoD, including the Defense Health Agency.

U.S. Veterans

WBD is uniquely positioned to assist U.S. veterans in potential CBPR projects. Founded in 2014 by a U.S. veteran as a Service-Disabled Veteran-Owned Small Business, WBD consultants, many of whom are U.S. veterans, understand the unique healthcare needs of U.S. veterans.

Recent research indicates that future partnerships between researchers and veterans are promising. In 2019, the Journal of Veteran Studies published findings from the <u>"Toward Veteran-Centered Research: Veteran-Focused Community Engagement Project,"</u> where 283 veterans and 101 stakeholders (e.g., veteran organizations and advocacy groups) in 6 states held 54 dialogs on the potential of engaging veterans in research partnerships.²⁵ Veterans identified their research priorities, articulated the barriers to research participation and partnerships, recommended how to engage veterans for research projects, and stated how they would like to receive research findings. From the conclusion of this study:

"The outcomes revealed from this veteran-centered community engagement project demonstrate that veterans want their voices to be heard regarding the aims, designs, recruitment activities, and dissemination plans related to veteran-focused research. The checklists developed as a result of this community engagement project represent a concrete step in this direction. With the help of these veteran-informed tools, research teams can operationalize this community's recommendations and move towards the goal of engaging veterans as true partners in the research enterprise."

- Flynn, L. et al. <u>Toward Veteran-Centered</u> Research: A Veteran-Focused Community <u>Engagement Project.</u> Journal of Veterans Studies, Vol. 4, No. 2, 2019.



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By collaborating with WBD, researchers initiating a CBPR partnership can benefit from the additional resources and expertise WBD offers. We are ready to help all partners make better decisions in CBPR projects and ensure that outcomes are aligned with community needs and aspirations.

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