

# Building a Community-Based Participatory Action Research Partnership: An Example from Western Alabama

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## COMMUNITY-BASED PARTICIPATORY ACTION RESEARCH (CBPR)

### What is CBPR?

A program of research that features:

- A prominent academic and community partnership
- A focus on participation, action, and research:
  - **Participation:** research is conducted “with” the community not “on” the community,
  - **Action:** research is geared towards helping the community make positive change
  - **Research:** the study uses a scientific approach to investigate answers to questions that affect the community
- Extensive collaboration throughout the project (Viswanathan et al., 2004) (i.e., “a reciprocal co-learner relationship between the researcher and the researched”)
- Stakeholder-relevant information that leads to action (Viswanathan et al.) (i.e., study results that provide “immediate and direct benefit . . . for taking collective action and effecting social change”)

### Who is involved in CBPR?

- Researchers/academics
- Stakeholders — Community organizations, Patient groups, Administrators, Lawmakers/Policy makers, & Physicians/Clinicians/Caregivers

### Why use CBPR?

- Greater external validity (effectiveness vs. efficacy)
- Interventions tailored to community and complex, real-life patients
- Improved insight into study results from stakeholders
- Rich ideas for future research
- Study outcomes tied to needs of community
- Feasibility related to real clinical sites/delivery systems
- Effective paradigm for health disparities research

## Method

Building on a pilot study (Thorn et al., 2011) and on-going relationship with a community partner (WHS), the current study sought to foster a formal, rich, reciprocal relationship with stakeholders (Viswanathan et al., 2004) to inform the design, content, and outcomes of the study and reduce observed health care disparities (Wallerstein & Duran, 2010). This was accomplished through multiple methods in a pilot study of 84 patients randomized to pain education or cognitive-behavioral therapy (CBT) treatment groups. The CBT intervention was revised and refined based on formal feedback from patients, clinicians, and community members. Methods included focus groups, patient feedback, qualitative interviews, and critical expert review. The resulting intervention showed evidence of efficacy for the treatment of pain.

In the most recent stage of this research program, the PI sought to formalize reciprocal connections with the community. Recruitment of a **Research Board** was initiated to guide future research. Composition of the board was informed by existing recommendations (Shalowitz et al., 2009; Viswanathan et al., 2004) and included academic researchers, administrators, clinicians, patients, and clinic staff members. This research board was tasked to meet regularly to identify research targets and questions; address concerns related to study conduct and design; review and evaluate study procedures, conduct, and progress; and aid in result interpretation and dissemination.

## References

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## CBPR In Action



## Abstract

**BACKGROUND.** Community-based participatory action research (CBPR) is a growing trend in health research because it integrates the goals of researchers with the needs, experiences, and expertise of the community. Rather than maintain a position of detachment, researchers are urged to engage the community under study, partner with them in all stages of the research, and work with them after the study to determine the best interpretations, uses, and messages from the results. The subsequent research is often more useful to the community and provides richer, contextualized information to the researchers, improving the strength of data interpretation and informing and improving future studies.

**OBJECTIVES.** To present a detailed description of a CBPR partnership and its development, which has led to a successfully funded project from the Patient-Centered Outcomes Research Institute.

**METHODS.** Building on years of experience working with community health care organizations, the primary author is joined by leaders of a community organization (Whatley Health Services; WHS) to describe their collaborative community–university partnership.

**RESULTS.** The poster reports a description of the development and current configuration of one CBPR program. Member perspectives, experiences, and recommendations are offered for prospective CBPR researchers. Difficulties initiating CBPR relationships (e.g., barriers to trust and credibility) can necessitate a slow approach to building community relationships, but the benefits (e.g., shared research funds, site-specific recommendations) can foster greater collaboration. Intentional inclusion of community stakeholders in research decisions provides important perspectives, knowledge, and expertise that enriches research designs, including outcome choices and measures, recruitment, engagement, retention, and interpretation/dissemination.

**CONCLUSIONS.** CBPR is an important method of conducting community-based research as it integrates the needs, experiences, and expertise of the community with the goals of the researchers to produce a rich, enduring, mutually beneficial research partnership.

**KEYWORDS:** community-based participatory research, community partnerships, patient-centered outcomes research

## Illustrations from Treatment Manual



## Results

The Principal Investigator, Dr. Thorn, met with the Chief Executive Officer of Whatley Health Services (WHS), Ms. Deborah Tucker, and a mutually beneficial relationship was agreed upon wherein WHS received pain groups and Dr. Thorn was able to test run the new intervention.

Initial board composition:

- Dr. Beverly Thorn, Study Principal Investigator
- Ms. Deborah Tucker, CEO of Whatley Health Services, Inc.
- Dr. Toya Burton, Chiropractor at WHS and Study Clinical Investigator
- Dr. Joshua Eyer, Study Research Psychologist
- Two patients from the pilot study (familiar with intervention)
- Additional members will include another clinician (a physician), 2 staff members, and a community member hired as the Study Recruiter.

The core of the Research Board has already met several times to discuss the project design, to troubleshoot problems, and to identify outcomes relevant to WHS. Board discussions highlighted a number of issues that were integrated into a subsequent grant proposal with a budget of \$1.3 million that was submitted to the Patient-Centered Outcomes Research Institute (PCORI). The proposal was funded in the first round with positive feedback about the rigor of the design and the focus on stakeholder integration. Currently, the Research Board is meeting to begin planning for the implementation of the grant and the execution of the study.

## Discussion

- A fundamental problem in health care research, particularly in groups experiencing large disparities, is the gap between the researcher and researched. CBPR offers a valuable, effective technique for closing this gap by integrating the community into the decision making for the study.
- Although it requires a greater investment, CBPR provides a step above patient-centered outcome research by including the voice, experiences, and opinions of the patients and care providers in the planning of the project. This inclusion improves the relevance of selected assessments, the usefulness of outcomes, and the interpretation of study results.
- The positioning of CBPR in the community facilitates the translation of research to action and to policy.
- In the example presented here, the integration of key stakeholders throughout the creation and early testing of a new treatment resulted in a more tailored and likely more effective intervention from the pilot study.
- The rigorous community-connection of the CBPR process helped craft a grant proposal that was funded in the first round by PCORI, one of only 25 proposals out of over 450.
- The Research Board is now meeting to plan the next phase of the study, which will involve completing the full board and hiring new study staff.

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## For Further Information

For additional information, contact the lead author, Dr. Beverly Thorn, at [bthorn@ua.edu](mailto:bthorn@ua.edu).