# Advancing Community-Based Participatory Research to Address Health Disparities in Hawai‘i: Perspectives from Academic Researchers

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## Abstract

*Community-based participatory research (CBPR) continues to be recognized as an effective research approach in which academic researchers work in partnership with communities to address health disparities. Although the literature suggests benefits associated with CBPR, more needs to be done to advance CBPR to ultimately reduce health disparities. Hawai‘i presents a research-rich opportunity for CBPR because of its ethnic diversity and geographic location, resulting in close-knit communities with unique experiences and concerns. This study aims to better understand the experiences of academic researchers who are conducting CBPR in Hawai‘i and their perceptions of its benefits and challenges as well as recommendations to advance the field. Twelve academic researchers with Hawai‘i-based CBPR experience were interviewed. Four major themes emerged from their responses: the importance of prioritizing relationship-building; reciprocal learning and other benefits of CBPR; navigating the tensions between CBPR and funding priorities; and building an academic setting that supports CBPR. Increasing awareness of CBPR and its benefits, as well as transforming the culture in all spaces where CBPR occurs may maximize its potential to ultimately promote health equity.*

## Keywords

*Community-Based Participatory Research, university, academia, faculty, qualitative research, community engagement, minority communities, culture, power dynamics*

## Abbreviations

*CBPR — Community-Based Participatory Research*
*U.S. — United States*
*NCBI — National Center for Biotechnology Information*
*IRB — Institutional Review Board*
*AI — American Indian*
*AN — Alaska Native*

Community-Based Participatory Research (CBPR) is an approach that aims to address pervasive health disparities in minority communities[1,2] and is defined as "a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings".[3] CBPR begins with a research topic important to the community and combines knowledge and action for social change to improve community health.[3] CBPR recognizes that community members have expertise on cultural knowledge, attitudes, rules of interaction, and context that shape the experiences of the community. CBPR advocates for community members to be equal and active partners in determining the research agenda and process and has shown promising results to address health disparities that affect diverse communities.[4-6]

Hawai‘i has one of the most diverse populations in the United States (U.S.) with three quarters of residents identifying themselves as Native Hawaiians, Pacific Islanders, and/or Asians.[7] The state has a high rate of interracial and interethnic marriages, with 50% of newborns being of mixed race/ethnicity.[8] Currently, one in four residents (24%) identifies as being multiracial.[8] Hawai‘i is often ranked as one of the healthiest states in the country because of the high average life expectancy and high rate of residents with health insurance.[9] In Hawai‘i, 52.3% of adults are reported to be overweight or obese,[10] compared to 70.2% of all U.S. residents.[11] In 2014, 9.7% of the population in the state had been diagnosed with diabetes and 14.4% had pre-diabetes compared to 9.3% diagnosed with diabetes and 27.8% diagnosed with pre-diabetes in the U.S. population.[12,13] Despite these outcomes that are above national averages, ethnic and racial health disparities in Hawai‘i disproportionately affect Native Hawaiians, the indigenous population of Hawai‘i, as well as other Pacific Islanders. For example, 14.8% of Pacific Islanders are afflicted with diabetes compared to 5% of Caucasians in Hawai‘i.[12] Life expectancy varies by ethnicity, which is 76.6 years for Native Hawaiians compared to 87.7 years for people of Chinese ancestry.[9] These disparities are due to the social determinants of health, such as educational and income disparities. For example, 18% of Native Hawaiians and Pacific Islanders are living below the poverty rate compared to the state average of 9.6%.[9] These ethnic disparities are rooted in the impacts of colonization that decimated the Native Hawaiian population as well as acculturative challenges faced by many Pacific Islander migrants.[14,15]

In addition to these disparities, a history of unethical research practices in the Pacific has led to community members' reluctance and wariness to engage with researchers who are not familiar with the community's culture.[16,17] For example, the U.S. government tested nuclear bombs in the region of Micronesia that destroyed human life and ecological systems of the islands.[18] Native Hawaiians have been also subjected to exploitive treatment by medical researchers, including the exile of Native Hawaiians with Hansen's disease to a remote northern

peninsula on the island of Moloka'i. Unethical medical studies were conducted by government physicians to identify the mode of transmission of Hansen's disease without consent or regard of this vulnerable population.[19,20] Community members also express their frustration with researchers "taking from the community without giving back to it," being disrespectful of cultural protocols, holding damaging stereotypical notions of their community, and providing no perceivable benefits to the community.[17] These behaviors lead to many communities to distrust research and researchers. CBPR principles, which are grounded in the long-term committment to relationship-building and sustainability, aim to establish research pathways that redress the distrust and the inherent power imbalances of the research enterprise.[1-3] These principles are (1) Recognize community as a unit of identity, (2) Build on the strengths and resources of the community, (3) Facilitate a collaborative and equitable partnership in all phases of research, (4) Integrate knowledge and action for mutual benefits of all partners, (5) Promote co-learning and empowering process that attends to social inequities, (6) Involve a cyclical and iterative process, (7) Address health from a positive and ecological perspective on multiple determinants of health, and (8) Disseminate findings and knowledge gained to all partners and involve them in the wider dissemination of results.

Given the ethnic diversity and unique socio-political context of Hawai'i, CBPR is an ideal research approach to address Hawaii's health disparities.[21,22] With CBPR projects steadily growing in Hawai'i,[22-26] the purpose of this study was to interview academic researchers who actively practice CBPR in Hawai'i and elicit their perspectives on CBPR benefits, challenges, and recommendations for future research praxis. This study was conducted through a public health graduate-level class at the University of Hawai'i Office of Public Health Studies. Six students from the course led the recruitment, data collection, and analysis with guidance from their instructor.

## Methods

### Participants

Academic researchers who have or are actively conducting CBPR across the state of Hawai'i were eligible to be recruited for this study. Participants initially were identified by searching the peer-reviewed literature for Hawai'i-based CBPR projects using "Community-Based Participatory Research," "Community Action Research," "Participatory Action Research" as well as "Hawaii" and "Hawaiian" as keywords. Databases that were used for literature search included PubMed, EBSCO, JSTOR, and other databases hosted by National Center for Biotechnology Information (NCBI). The database search was conducted in September-October of 2016. Names of researchers identified by the database search were compiled with names of CBPR researchers who were known to the students and instructor.

Snowball sampling was used to identify and recruit other CBPR researchers in the study. Snowball sampling is a common technique for recruiting study participants that are hard to reach or difficult to identify due to narrow eligibility criteria, such as the present study. Current participants were asked to refer other CBPR researchers from their personal networks based on participant eligibility.[27]

### Measures

A semi-structured interview guide comprised of 10 questions was developed de novo by the group of graduate public health students working on this study as part of their coursework. The interview guide was tested with the instructor of the class (JCD), who is also a co-author of this study. Questions were designed to capture participants' motivation for conducting CBPR, perceived benefits and challenges associated with CBPR, and their recommendations on how CBPR could be advanced in Hawai'i. A total of twelve interviews (seven in-person, and five by phone) were conducted based on participants' preference and availability during the interview phase of the study. Interviews were scheduled during the semester in which the students were enrolled in the course. Interviews lasted between 30-120 minutes. All participants provided oral consent. To ensure accuracy of understanding, interviews were audio-recorded and notes were taken by student interviewers. Study procedures were approved by the University of Hawai'i Office of Research Compliance.

### Data Management and Analysis

Interview notes were first transcribed by the interviewer and then verified with audio recordings. Each transcript was de-identified and analyzed using content analysis. First, each transcript was individually reviewed by one or more members of the student research team to identify descriptive codes based on the interview guide. Codes were defined from a reoccurring word or a short phrase related to specific concepts and constructs that predominately emerged from the interviews for each interview question.[28] These codes emerged from the data, as opposed to being fitted into previously defined codes. Second, the group of student researchers convened to discuss each code, then grouped the codes into preliminary themes using consensus coding. Third, the preliminary themes were shared and validated with participants at an in-person dissemination gathering. Those who were not able to attend were provided a copy of the completed paper and were asked to provide comment and/or feedback. Based on the participants' feedback, themes were refined and the final themes are presented below.

## Results

Twelve CBPR academic researchers participated in the study. Other CBPR researchers expressed interest in participating but were not available for the interview phase of the study. The majority of participants were employed by the University of Hawai'i at Mānoa with 11 affiliated with the University of Hawai'i at Mānoa and one affiliated with Hawai'i Pacific University. Three were male and nine were female. Participants had an average of 19 years of experience conducting CBPR, with 16 of these years in Hawai'i (across the state). Ethnici-

ties of participants included Native Hawaiian, Filipino, Maori (the Indigenous people of Aotearoa New Zealand), Japanese, African-American, and Euro-American. Participants came from diverse academic disciplines and research areas, including social work, public health, gerontology, health science informatics, indigenous studies, nursing, and behavioral and mental health. Current employment status of participants ranged from lecturer, research faculty, instructional faculty, and administrators. All worked on research that included community partners in O'ahu as well as in neighboring islands. Participants reported receiving funding from various sources, such as nonprofit, and state and national government agencies to conduct CBPR in Hawai'i.

Four major themes emerged from the content analysis: the importance of prioritizing relationship-building; reciprocal learning and other benefits of CBPR; navigating the tensions between CBPR and funding priorities; and building an academic setting that supports CBPR. There was much agreement among the participants throughout the interviews and across the themes.

**Theme 1: Importance of prioritizing relationship-building**

All participants emphasized the importance of prioritizing relationship-building to learn about the specific cultures and contexts of each community that they are partnering with. Relationship-building was considered essential to cultivate a place-based understanding of specific communities in Hawai'i, and to avoid making assumptions and generalizations that may hamper the CBPR process. As one participant stated, *"CBPR researchers have to make a long-time relationship with the community. To me, it is necessary, it is the process."*

CBPR approaches were viewed as aligning well with the cultures of Hawai'i, which tend to be collectivistic and relational. Collectivism and relational emphases were attributed to the indigenous host culture as well as the significant presence of Asian and Pacific Islander communities. An aspect of relationship-building is the awareness of positionality in terms of insider/outsider status, which participants recognized as important for navigating community dynamics. As one participant stated, "*in Hawai'i, we are relationship driven. There is sense of an outsider/insider mentality.*" The importance of outsider researchers needing to take the time to engage in an authentic relationship-building process by demonstrating their commitment was also emphasized in the responses collected. "*A lot of these smaller communities are all families. You are invited into very tight-knit communities. You will be spending a lot of time there, you need to demonstrate that you are real and that you care about them and their community.*"

**Theme 2: Reciprocal learning and other community benefits of CBPR**

Words used to describe the benefits of CBPR were *collaboration*, *recognition, research insight, confidence,* and *active participation*. The reciprocal learning process and recognizing the community's expertise can positively shape and guide the research process, which produces lasting and direct benefits to the community. As one participant expressed, *"they are excellent partners because they can define the need, what the project should be about, and what would work/not work within their organization."* Another participant spoke about how collaborating with community members can help: "*researchers identify and learn new approaches that they may not have thought about prior to collaboration within the community."* CBPR can also create a *"comfortable space"* for community members to connect and engage with researchers and academia. Participants reported that this has helped transform the community's prior perceptions about research and academia, which often is perceived to be a disconnected enterprise occurring in the *"ivory tower"*. As a participant stated, *"community exposure, engagement, and involvement in research can lead to interest in how research can benefit [the] community."* Furthermore, CBPR's principle to share and make the findings accessible to the community allows for community members to be informed and able to take action. This point was summarized by a participant who stated, "*CBPR can serve as a bridge between the community and those in academia. Policy change can happen when academia and the community work together.*"

**Theme 3: Navigating the tensions between CBPR and funding priorities**

Regarding challenges, CBPR principles unanimously were viewed as conflicting with institutional expectations. For example, building trusting relationships is a necessity of CBPR, but academic time constraints were repeatedly mentioned as a challenge to fulfilling this principle. As one participant stated, "*from a science perspective, the grants are very time-limited. It takes years to establish relationships in communities. Trying to convince funders you need a lot of time is a challenge.*" They also expressed the need for funders to allow for more *"flexibility in research designs."* Many expressed that this would be helpful in conducting CBPR, which tends to be iterative and dynamic. The challenge of short-term funding was also raised as posing barriers to sustaining programs and services. Once a grant ends, finding resources to sustain the efforts initiated was often cited as a major challenge: "*Funding is always a challenge especially after the grant period. You want to be able to sustain the new program/model."*

Participants acknowledged the nature of research funding, which traditionally is awarded to universities, poses challenges to truly addressing power imbalances. Although CBPR promotes community members as equitable partners in research and intellectual leadership, upholding this in practice was notably difficult. Participants recognized this predicament and stated the need for more systematic support to build capacity within the community so that research leadership may be equitable.

**Theme 4: Building an academic setting that is conducive to CBPR**

Multiple ideas and identified challenges to advance CBPR in academia were given. For instance, participants spoke about the lack of high-impact journals that publish CBPR findings, lack of academic incentives in community dissemination activities, such as producing and distributing community-friendly research products, and the need for other avenues for publication, such as a *"Web journal for CBPR products [that] would count towards tenure*." Integrating CBPR principles and priorities into the Institutional Review Board (IRB) process was also cited as playing an important role in advancing CBPR. "*The IRB needs to be aware of CBPR. IRB requires specific roles in research… only one person can be the principal-investigator and not more than one. Therefore, educating IRB about the specific roles of CBPR is necessary.*"

Furthermore, CBPR generally was perceived to be unknown to bench and biomedical researchers, and thus problematic because academic standards for conducting studies is conducive to lab research, but not appropriate for CBPR. These limitations and constraints restrict the CBPR process and diminish the potential and capacity of CBPR's benefits. If universities gave greater recognition to CBPR and the work it entails, there may be more support for this approach to be integrated and promoted across various fields and disciplines. Offering more training in CBPR across disciplines was suggested to potentially increase the number CBPR researchers to advance the field. This was summarized by a quote from one of the study participants: *"A lot of people don't understand it. [We need] more training on what good CBPR research is and why it's important to conduct it. [We need] more people who do it and more people who could train people to do CBPR."* Responses collected also reported encouraging students to analyze and question CBPR practices from the past, and critique what is currently in place by asking, *"Are current CBPR practices, policies, and procedures effective? If not, why are they ineffective, and what can we do to improve and make changes that will benefit everyone?"* Another recommendation was to create "*interprofessional and interdisciplinary collaboration, like writing groups"* to build CBPR learning communities across academia.

## Discussion

The mission of many universities often includes a call to serve the community. Despite the progress that has been made in partnering with communities, academic institutions, are often seen as "ivory towers" that are not accessible and friendly to the community.[29] Community members do not always see the direct benefits and social action of the research and instead perceive research as a distant activity, that is disconnected from the community's lived experiences. CBPR offers a way to shift the paradigm of research to promote equitable partnerships between communities and academic researchers. With CBPR projects steadily growing in Hawai'i,[22-26] it is necessary to understand how CBPR is being conducted and identify the facilitators and barriers of conducting this type of research approach.

The findings of this study suggest that the foundation of CBPR is based in relationship-building that leads to reciprocal learning between academia and the community. To support the relationship-building process, systems-level changes may be needed to demonstrate and realize the full benefits of CBPR. A key finding in this study focused on the relationship between the researcher and community as a major influencer of CBPR. The importance of trusting relationships in CBPR research has been found by other studies.[16,-17, 21-26] Jagosh, et al, found that investing in research partnerships can potentially lead to significant returns unforeseeable prior to the start of the project.[30] Establishing and maintaining a long-term relationship with community may take on even more prominence in Hawai'i due to the collectivist nature of the many small, tight knit communities.[17,21]

Although Hawai'i is a relatively small state with approximately 1.4 million residents,[31] it is the most diverse state in the nation. CBPR has helped researchers to recognize the nuanced differences in needs and resources between various communities across the islands. Furthermore, the community's involvement can influence policy changes to directly address the community's needs and promote sustainable collaborations.[20] Continual co-learning can increase community ownership and co-governance, which is essential to making systems change to advance initiatives.[32-34]

Building trusting relationships in CBPR is challenged by systemic barriers identified in this study, such as the academic promotion system and funding structures, which have been documented in other studies.[35-36] Investments such as time and funding are required to build strong academic-community partnerships. This creates tensions between the requirement of the researcher's institution and funding sponsor and the requirements of building a strong community-academic partnership .[30] In an assessment of how well federally-funded community network programs integrated CBPR principles, most programs scored well on conducting strength-based and action-oriented projects that facilitated co-learning and capacity-building but scored lower on equitable sharing of resources and sustainability.[32]

Although some evaluations of federally-funded CBPR have suggested that achieving equality is genuinely unrealistic due to an underfunded service orientation of community partners and the social and institutional systems that perpetuate imbalances of power,[35] participants in this study provided suggestions to address these tensions. These suggestions are also reflected in the wider CBPR literature, such as integrating community dissemination efforts in tenure and promotion guidelines,[36] increasing the number of high-impact CBPR journals, implementing CBPR trainings for students and junior researchers,[37] and infusing CBPR principles and practices into institutional research ethics review boards.[29] These suggestions may be conducive to universities that integrate the importance of community engagement and placed-based learning in their mission or strategic plans, such as University of Hawai'i, which is a land-grant insititution and has the mission of cultivating a Hawaiian Place of Learning.[37] Others suggested using evaluative measures to assess the partnering process and outcomes.[38]

A study by Allen, et al,[39] recommended providing education and facilitation programs to support partnership building, and to increase the capacity for CBPR within communities and research institutions. Previous literature also emphasized the importance of recognizing one's biases from the researcher's perspective and understanding how researchers' inherent identity and privilege can influence the quality of CBPR studies.[30,34] Because the importance of relationships in small close-knit communities of Hawai'i were emphasized by the participants, the *Hilina'i*: *Trust and Cultural Safety in Research Praxis* framework may serve as guidelines and a teaching tool for students and researchers who hope to collaborate with communities to conduct CBPR.[17] *Hilina'i* is a Hawaiian word for "trust" and also serves as a mnemonic to emphasizes the importance of: **H**onoring community history of strength and resilience, **I**ntrospecting of one's biases, **L**earning community ways of knowing and transmitting knowledge, **I**nvolving oneself in community activities, **N**urturing meaningful community participation across the phases of the research, **A**cting to enhance research capacity of the community, and **I**nsurrecting relationships of unequal power and control though culturally-grounded processes. Using similar placed-based frameworks that are grounded in the worldview of the specific community that researchers hope to work with may advance the field of CBPR. Participants in this study also suggested integrating community members into CBPR trainings to promote the exchange of knowledge and co-learning. Furthermore, the community's involvement can influence policy changes to directly address the community's needs and promote sustainable collaborations.[40] Continual co-learning can increase community ownership and co-governance, which is essential to making systems change to advance initiatives.

## Limitations & Future Directions

The findings of this study were based on the responses from twelve CBPR researchers in Hawai'i. Participants came from diverse fields, but were limited to university-based researchers residing on the island of O'ahu with the majority affiliated with the University of Hawai'i at Mānoa. Academic researchers from colleges including community colleges in the neighboring islands, which are primarily rural and recognized as underserved areas, were not recruited for this study. However, the majority of the participants have conducted or currently are conducting CBPR across the State of Hawai'i. In addition, this study only focused on CBPR researchers who are situated in academic settings and affiliations. To expand on the present study and the extant literature, future studies could focus on gathering the perspectives from organizations focusing on Native Hawaiian health and/or minority health, and community partners and community researchers who have been or are involved in CBPR.[17,21] In addition, CBPR would benefit from studies that examine the structural factors that impede or promote CBPR with populations that are relevant to Hawai'i's context. For example, a review of federally funded community engaged research studies indicated that American Indian (AI)- and Alaska Natives (AN)-serving projects have higher rates of written partnership agreements, research integrity training, and data ownership.[34] However, these AI/AN projects receive less federal funding, yet have comparable research productivity compared to research with other communities of color. It would be important to assess if this pattern of funding and outcomes applies to CBPR occurring in Hawai'i.

## Concluding Remarks

The results from this study suggest that there should be more CBPR trainings offered to students and researchers to promote CBPR, as well as bring awareness to this research approach. Also, research review boards may need to consider different types of research by adjusting their submission process so it's more inclusive of studies like CBPR. Lastly, institutions could modify their criteria for tenure and promotion to value the activities in which CBPR researchers engage, such as allowing researchers more time to build relationships with a community and have community members involved in every step of the research project. CBPR has the promise to close this gap to ensure that communities benefit from the research enterprise. Insights shared by the CBPR researchers in this study can play an important role in advancing CBPR to address health disparities and promote health equity.

## Conflict of Interest

None of the authors have any conflict of interest to report.


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