RESEARCH ARTICLE

Linking health education, civic engagement, and research at a large Federally Qualified Health Center to address health disparities

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Abstract

Objective: To develop a framework for patient-centered research in a community health center.

Study setting: Primary organizational case-study data were collected at a large Federally Qualified Health Center (FQHC) in Southern California from 2019 to 2021.

Study design: Thirty stakeholders, including patients, community leaders, students, medical providers, and academic partners, participated in community-engagement capacity-building exercises and planning. These activities were guided by Community Based Participatory Principles and were part of an initiative to address health disparities by supporting patient and community-engaged research.

Data collection: The study included an iterative development process. Stakeholders participated in a total of 44 workgroup meetings and 7 full-group quarterly convenings. The minutes of the meetings from both workgroups and quarterly convenings were used to document the evolution of the initiative.

Principle findings: Stakeholders concluded that health equity research needs to be part of a larger engagement ecosystem and that, in some ways, engagement on research projects may be a later-stage form of engagement following patient/community and staff/researcher coeducation and cocapacity building efforts.

Conclusions: Community health center stakeholders viewed successful engagement of community members in patient-centered health equity research as involving a

web of longitudinal, evolving internal and external relationships rather than discrete, time-limited, and single-project-based dyadic connections.

KEYWORDS

community medicine, federally qualified health centers, health disparities, health equity, Latinx, participatory research, Social Determinants of Health

What is known on this topic

- Models for facilitating Community Based Participatory Research (CBPR) approaches within community healthcare settings remain underexplored.

What this study adds

- Health This study examines how a group of community health center stakeholders developed recommendations for how to embed CBPR in an ecosystem of community engagement to address health equity through research and policy change.
- Stakeholders viewed engagement in health equity research in a healthcare setting as requiring sustained internal and external relationships on an array of connected topics, including health education, research, and advocacy efforts.

1 | INTRODUCTION

Health inequalities are differences in health outcomes that are avoidable, unnecessary, and unjust.[1,2] Systemic inequities in economic, social, and environmental factors create differential obstacles to health.[3] Black, Indigenous, and People of Color are disproportionately impacted by health inequalities that continue to be shaped by structural racism, which limits access to critical resources and opportunities.[4] There is growing recognition that achieving health equity is an ethical imperative for healthcare professionals.[5] However, the structural pathways for healthcare systems to reduce disparities are less clear, as systemic change often requires political will and local action traditionally seen as outside of the healthcare purview.

Research has been instrumental in providing evidence of inequalities in health outcomes and supporting a need for programs and policies to address these gaps.[6–8] Yet, translating findings into action is challenged by the limited ability of researchers, including those employed by healthcare systems, to link evidence-based practices to civic mobilization and policy advocacy.[9] A key aspect of this limitation is the historical disconnect between researchers and the communities they study. To bridge this divide, Community Based Participatory Research (CBPR) has been advanced.[10] CBPR emphasizes engagement with community members throughout all stages of the research process, from identification of the research question(s) to the dissemination of study results.[11,12] CBPR opens the door for partnership with communities historically excluded from research and empowers individuals from whom data comes to lead health equity advocacy efforts.[9,13]

Given their proximity to groups negatively affected by inequalities, community health centers are appropriately positioned to implement CBPR approaches. Health centers provide critical health services,

function as trusted institutions, and often have deep relationships with their surrounding communities. Yet, while community engagement has been considered important to the design and conduct of health research and policy for close to 20-years, its use is much newer in health services and clinical effectiveness research.[14,15] Consequently, there is little evidence on how community health centers can facilitate CBPR approaches, specifically key practices for initial and sustained engagement.[16] This study aims to address this limitation by focusing on lessons learned from the efforts of a large Federally Qualified Health Center (FQHC) to link health education, research, and community advocacy efforts with the aim of reducing health disparities. These efforts occurred under the Health Equity and Access for Latinos through Patient-Centered Outcomes Research Capacity-Building (HEAL through PCOR) initiative, a multiyear capacity-building program funded by the Patient-Centered Outcomes Research Institute.

2 | METHODS

2.1 | Setting

HEAL through PCOR was launched as part of AltaMed Health Services's efforts to increase its ability to engage community/patients as research partners. AltaMed serves over 320,000 low-income patients in Southern California experiencing a range of poor health outcomes, including high rates of hypertension, diabetes, and asthma.[17]

In 2017, AltaMed launched an Institute for Health Equity to focus its efforts to address health disparities through research, evidence-based interventions, education, and advocacy. As a result, AltaMed became one of the only FQHCs across the nation to house a research department with independent investigators. The research team includes several research scientists and a community-engaged research core.

Institutional funds helped initiate these teams, with grant funding providing for sustainability and growth. Prior to the institute's launch, AltaMed partnered with external researchers in conducting traditional health services and clinical effectiveness research. However, partnerships were not systematically vetted, and there were no standard requirements for collaboration. With its own research department, AltaMed was able to reassess its partnership practices and establish a framework for internally led research projects, which would also move beyond traditional clinical effectiveness and health services research to examine the social determinants of health.

Historically, research at FQHCs has been led by external partners, but there is a growing desire to increase internal capacity as seen through national toolkits,[18] collaborative data projects,[19] and efforts to diversify participant pools for clinical trials.[20] However, there are no standards governing how FQHC research departments are led or how they may be set up differently from traditional academic centers. HEAL through PCOR became one of the first initiatives led by the institute and allowed the organization to examine its research and engagement practices.

2.2 | Study design

This study used a participatory research approach that consisted of an iterative development process with active stakeholder engagement. Stakeholders participated in monthly workgroup meetings and quarterly convenings. The initiative did not focus on identifying research topics but instead prioritized the development of a comprehensive plan for patient/community engaged-research at the FQHC. Three workgroups were established: committee aims and governance, community engagement strategy, and research priority setting. The committee aims and governance workgroup was charged with developing a plan for sustaining community engagement long-term; the community engagement strategy workgroup focused on community/patient engagement practices, including recruitment and capacity building to partner in and lead research; and the research priority setting workgroup was charged with identifying process tools for ensuring research was community/patient-centered and embodied CBPR principles. In addition to workgroup meetings, all stakeholders came together quarterly to discuss opportunities for cross-departmental collaboration and common challenges. CBPR principles served as the foundation for relational and collaborative processes,[21,22] as well as calls for the institutionalization of community engagement as both a strategy for and an outcome of the research. The right balance between research and action was also discussed.[21] Minutes taken during all meetings tracked the evolution of the team's vision.

2.3 | Stakeholders

HEAL through PCOR, convened an advisory committee of more than 30 stakeholders, including patients, community leaders, medical providers, patient advocates, academic partners, and college and graduate students recruited from across AltaMed community/patient-facing programs, services, and partner organizations. Initial stakeholders were identified by institute leadership based on previous experience with partnered research and community engagement efforts. Further, early participants were asked to extend an invitation to colleagues whose interests or work intersected with project aims. Stakeholders included a core group of five FQHC programs and research staff that participated in the initiative and provided administrative support for the effort. Several HEAL through PCOR stakeholders had previous experience with patient-centered outcomes research, and roughly half self-identified as having grown up or as currently living in communities served by the FQHC. Stakeholders expressed alignment with the goals of designing formal mechanisms to expand and integrate into research activities the principles embodied in the FQHC's existing community empowerment programs and civic engagement efforts.

3 | RESULTS

3.1 | Resulting framework

Stakeholders articulated a desire to decrease silos and increase collaboration across the organization to ensure that community engagement initiatives were complementary and non-duplicative. Prior to HEAL through PCOR, stakeholders identified the FQHC's community engagement systems as fragmented, focused on single-touch, transactional models, and lacking formal structures to support long-term capacity-building and leadership among community members. In contrast, HEAL through PCOR stakeholders viewed an ideal system for engagement as one that would be relational, long-term, and focused on power-building among historically excluded communities. There was also a belief that having multiple FQHC efforts to address health inequalities, including health education and policy advocacy, could function synergistically.

Stakeholders surmised that limiting engagement to research would be inadequate. Various programs at the FQHC, including health education, could be leveraged to facilitate initial engagement and could be more natural and community-relevant entry points for long-term partnerships than research. As a result of cross-workgroup sessions that brought together diverse group perspectives, stakeholders developed a conceptual model linking the FQHC's health education, civic engagement, and research efforts (Figure 1). Adapted from Cacari-Stone et al.'s model illustrating the link between CBPR and policymaking,[9] the FQHC's model embeds participatory processes within a healthcare system and includes contexts, CBPR processes, policymaking, and outcomes. At the crux of the FQHC's framework is the recognition that each stage in the model is unique yet potentially interconnected and complementary.

In the contexts domain of Figure 1, HEAL through PCOR stakeholders conceptualized health education as an entry point to sustained engagement activities such as advocacy and participatory research. Stakeholders identified macro-level factors, including communities' historical context, as guiding curriculum development for
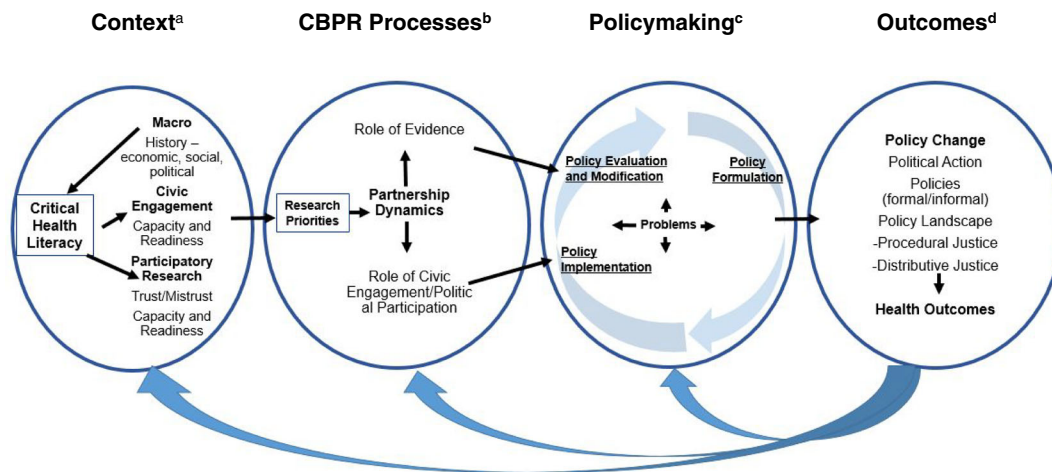
FIGURE 1 Conceptual model linking health education, community-based participatory research (CBPR), and policymaking. Adapted from Reference 9. [a]Contexts include macrolevel factors such as a community's history and social-economic factors. It also encompasses opportunities for members to build capacity for engaging in policy and research processes. [b]CBPR processes encompass research partnerships in action, including how these develop evidence for civic engagement and policy action. [c]Policymaking considers strategies for action, including what policies stakeholders advocate for and how they are informed by evidence generated by research. [d]Outcomes focus on what political action is taken to create change and the impact of policy and program change on health outcomes [Color figure can be viewed at wileyonlinelibrary.com]

health education initiatives. Previously, health education only focused on behavioral change at the individual level. However, stakeholders identified the need to move beyond the individual to contextualize health within an environmental and social context, highlighting how socioeconomic factors can enable or constrain health behaviors. For instance, under the proposed approach, a diabetes management program would discuss how individual behaviors impact the development and management of diabetes but would situate such behaviors within environmental facilitators and barriers. Further, health education programs would move beyond providing facts to connecting individuals to opportunities to act toward health equity, including linkages to civic engagement and participatory research initiatives.

Context also includes community capacity to engage in efforts to impact change. Due to the historical exclusion of some racial and ethnic groups in both research and policymaking, the community engagement strategy workgroup stressed the importance of having community engagement strategies include capacity building as a central component. Workgroup members emphasized that capacity building efforts include two separate but interrelated components, (1) a focus on policy impact and the advocacy process and (2) an overview of what research is and how it can be used as a tool for change. Capacity building was seen as critical to support self-efficacy and an understanding of how to enact structural change. As part of HEAL through PCOR, the FQHC developed a research training program for community members. It also expanded its advocacy leadership curriculum to include a session on how research can impact policy and program change. Community members are invited to participate in one or both programs. These capacity-building efforts provide a general orientation to research and advocacy processes while allowing participants to explore specific topics of interest through small-group projects. Under the

proposed model, community/patients that participate in capacity-building programs identify research priorities for partnered research projects. The research priority workgroup believed such topics could then be used to build community requests for proposals, which would function as a way for community leaders to put out calls for researcher partnerships.

In Figure 1, CBPR processes emphasize the role of research as a key part of evidence-based programs and policies and intentionally include community members that have firsthand knowledge of how these affect daily living. Under participatory research approaches, researchers play a critical role in building trust and facilitating collaboration. Researchers must be willing to respect and learn from community members' experiences while also sharing their knowledge and tools in support of community interests and goals. HEAL through PCOR stakeholders, acknowledged that a CBPR approach would constitute a cultural shift away from current research practices, which focus on researcher-initiated projects that view community members as subjects instead of as partners. The committee aims and governance workgroup noted that this reorientation requires the FQHC to invest in researcher capacity to understand and implement CBPR principles, but also to create processes that hold researchers accountable in abiding by these values. Consequently, the research priority workgroup revised guidelines for externally initiated research projects to require that community-centered approaches be embedded early on in partnerships. Changes to the process included requiring researchers to state how their project will impact health inequities, how they will partner with community/patients, and how they would ensure that findings are shared back with relevant stakeholders. Further, all FQHC independent researchers were involved in HEAL through PCOR and agreed that CBPR values were critical to the work they aimed to lead at the FQHC.

Stakeholders expressed that the ultimate aim of CBPR should be to use findings to co-develop campaigns for program change and policy action. The FQHC currently leads advocacy efforts, but priorities have been set by FQHC leadership. Stakeholders identified CBPR as a tool to partner with community members to set advocacy goals and develop evidence for policy recommendations. By building on the diabetes example above, a CBPR project focused on food insecurity and diabetes might uncover that access to healthy food has significant impacts on a patient's ability to manage their diabetes. Consequently, CBPR participants might work with the health center to investigate opportunities to expand supplemental food benefits and collaboratively advocate for program change. In this manner, research findings would directly inform the FQHCs advocacy work. Acknowledging that policymaking is a long-term commitment, the committee aims and governance workgroup was supportive of the FQHC establishing an organizing institute to engage community members in ongoing policy change planning.

Last, the large arrows in Figure 1 depict the impact of policy outcomes on future cycles of engagement, including how education, research, or mobilization processes might shift to impact system change more effectively.

4 | DISCUSSION

Community health center stakeholders developed a conceptual model that identified the need for CBPR to be embedded in a comprehensive engagement system. Such a system could provide opportunities ranging from health education and evidence generation to policy identification and political mobilization, all with the aim of eliminating health inequalities. The initial entry point to research for communities may be through mechanisms such as health education efforts that are more immediately connected to understandings of their own and their community's health, particularly efforts that evolve from those defined as "functional" in reports on health literacy design (basic understanding of facts) to "interactive" (participant decision making) and "critical" (understanding socioenvironmental contexts).[9,23] Subsequently, research and policy advocacy can be introduced as tools to change the systems and structures that affect well-being over longer time horizons.

While educational opportunities may be an entry point to engagement, capacity-building programs were seen as essential to understanding the process for change, empowering community members with the tools needed to take action, and building a sense of self-efficacy. Capacity-building programs require significant resources and long-term organizational commitment but enable the use of CBPR as a tool for change.[24–28] Having capacity building be a focus prior to CBPR engagement was viewed as allowing community members to enter research partnerships only after being able to identify what they are interested in changing (through health education), how they want to create change (through policy), and what information they need to inform the policy and programs they desire (through research).

HEAL through PCOR gave the FQHC an opportunity to reflect on health equity research and advance toward centering community/patients in informing this work. While significant progress was made under HEAL through PCOR, stakeholders acknowledge that the first 2 years of the program were only the start of a long-term effort to strengthen the role of community voices at the FQHC. The next steps will include: (1) ongoing engagement of HEAL through PCOR stakeholders in the form of an oversight committee that will ensure that their recommendations for community/patient engagement are put into practice; (2) continued investment in community/patient capacity to learn about and engage with research efforts; (3) ongoing efforts to increase cross-departmental collaboration; (4) work to identify community/patient concerns and center these in plans for action that comprise a spectrum of change activities, including health education, research, and advocacy; and (5) the FQHC will continue efforts to shift the organizational culture to embrace CBPR values, which acknowledge the critical role of community/patients in reducing health disparities. Ultimately, stakeholders emphasized the need for sustained, interwoven commitments of resources to community engagement through internal and external relationships developed over iterative interactions and partnerships. Implementing CBPR represents a social justice and human rights value-based system, and investing in these relationships was seen as a prerequisite to authentically advancing coempowerment and shared learnings with the communities that are the focus of efforts to advance health equity.[9,29]

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