

# Interrogating academic hegemony in community-based participatory research to address health inequities

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## Abstract

Community-based participatory research holds promise for addressing health inequities. It focuses on issues salient to specific populations, prioritizes community engagement and amplifies the voices of marginalized populations in policy formulation and designing interventions. Although communities are partners, academic hegemony limits their level of influence over the research initiative. Drawing from our own collaborative research experiences, we raise questions for community-engaged health services researchers to reflect upon as a means of interrogating academic hegemony in partnerships that seek to address health inequities. We describe what it means for researchers to acknowledge and relinquish the power they wield in the community-engaged health services research enterprise. We propose three guiding principles for advancing equity: authentic engagement, defining and living values, and embracing accountability.

## Keywords

Community-based participatory research, equity in population health research, community engagement

## Introduction

Community-based participatory research (CBPR) is an approach to research, intervention development, implementation and evaluation in which researchers work as equal status partners with community members throughout the research process.<sup>1</sup> This partnership jointly determines the focus of research, and all partners are equally invested in its implementation and dissemination. In the last decade, CBPR has become the gold standard to population health research that seeks to reduce inequities because it engages those most affected.<sup>1,2</sup> But as this approach gains popularity, the challenges to ensuring that communities are in equitable control of the research initiative have become more visible.<sup>3–5</sup> Researchers using the CPBR approach continue to hold significant influence over the research process. This domination is what we here define as ‘academic hegemony’, describing unequal power relations between researchers and community members. In this essay, we interrogate academic hegemony by reflecting on issues of power and equity in our own community-engaged health services research project. We propose three guiding principles to help researchers shift power imbalances and advance equity in CBPR.

## Our partnership

Beginning in 2017, our team, consisting of a health care, a community organizing, and an academic activist, have worked on addressing inequities in a range of health outcomes in Allentown, Pennsylvania. The clinician and health care activist has led several CBPR projects including implementing community-based care management for people with complex health and social needs. The community organizing partner leads a local non-profit that serves as a hub for transformative community leadership and empowerment. The

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A local community health survey indicated that exclusion was a significant issue affecting wellbeing in the local population. In response, the research team held a series of meetings with diverse stakeholders from community health, civic engagement and social service organizations, for profit and not-for-profit hospitals, education, law enforcement and faith leaders. Meetings sought to develop research objectives around understanding the causes and dimensions of social exclusion, as well as its consequences on wellbeing and access to care. During these meetings, attendees agreed that the research team conduct focus group conversations with members of marginalized populations, which we defined as groups that are systematically excluded from full rights, privileges and opportunities, and who might lack economic and political resources needed for full social participation. In the context of our work these were Black and Latinx populations, immigrants, lesbian, gay, bisexual and transgender persons, and people living in poverty. Stakeholders from health and social services organizations identified community connectors, that is, residents focused on knowing their neighbours' needs and connecting them to resources, who then explored ways to engage hard-to-hear populations of interest. Hard-to-hear persons in our study were those who belong to groups marginalized by structural inequalities and who our stakeholders identified as having stopped showing up to receive services or who were experiencing housing insecurity. We also included formerly incarcerated and justice-involved individuals as well as people in recovery or who were actively using substances. These populations have been historically excluded because their perspectives are often not prioritized when identifying policies to meet their needs.<sup>6</sup> In the following, we refer to stakeholders from different sectors, connectors, and hard-to-hear marginalized populations as community members who can play a central role in addressing health inequities. Our research partnership has relied on their leadership and experiences to begin to understand dimensions of exclusion within the health care setting, the mechanisms that reproduce it, and its consequences on health outcomes. However, academic and community partnerships in CBPR are fraught with academic dominance that limits levels of community influence over the research initiative. Limited community control restricts our understanding of the perspectives of communities and our ability to co-create interventions that are grounded in these perspectives. Without interrogating the power that sustains academic hegemony, researchers might inadvertently contribute to the reproduction of oppression and privilege that maintain the very same health inequities they seek to address.

## State of community partnerships in health services research

The community (patients, stakeholders, and populations not part of the research team) is central to research and to the delivery of care. Health services researchers engage the community in a variety of ways. At one end of the continuum, community engagement is limited to consultation and advice, helping to facilitate recruitment of participants and gaining an understanding of the population's unique circumstances (strengths, needs, perspectives, and preferences). At the other end are community members as co-investigators<sup>7-9</sup> and beyond such as in user-controlled research where communities define their participation and are in charge of their epistemic contributions.<sup>10</sup> The co-investigator and user-controlled approaches are typical of CBPR and are associated with more effective and self-sustaining interventions than conventional approaches to involving communities in research.<sup>2,10,11</sup> This understanding of continuum of community engagement in CBPR reflects, at least in part, Arnstein's ladder of participation that assesses citizens' power in shaping the outcome of a participatory process.<sup>12</sup> There are gradients in participation. For instance, citizens can participate by serving as informants, consultants, partners in shared decision-making, or by exercising full control over decision-making processes. In the ladder model, forms of participation such as informing and consulting do not involve shifts in power to citizens.

Thus, not all participation is necessarily empowering and this can be the case in CBPR, too. Researchers still determine whether and how the input, perspectives and contributions of community members are used. This is due, in part, to the inability of researchers to align a community-driven research agenda with their own agenda or those of their funders,<sup>5</sup> as well as institutional requirements around who can be a principal or co-investigator, and what those roles entail.<sup>13,14</sup>

Researchers also tend to not explicitly interrogate the power that sustains academic hegemony in CBPR. We conceptualize power as the dynamic ways by which status, access to information and resources, and control of the means of knowledge production shape research relationships, decision-making, and research outcomes. Thus, power is the "ability to influence the allocation of research resources, engage players and shape policy."<sup>15,p.11</sup> For example, who determines the research objectives? Who decides on participation, recognition and compensation? Without dismantling academic hegemony, participation by a community with limited control of the process might be exploitative.<sup>3,16</sup> This might affect the representativeness and validity of the data, and research findings only

partially reflect actual community experiences and perspectives (or not at all). Ultimately, it becomes harder to translate research findings into policy and practice that would improve health outcomes, and this can lead to greater mistrust of researchers among the community.<sup>11,17</sup>

### **Interrogating power**

Any CBPR approach should explicitly interrogate power. Researchers must fully embrace what it means for community members to be equal partners; community members are context experts and leaders and should have equal control over the research process. Context experts are those with experiential knowledge of the conditions and situations that are the focus of the research.<sup>18</sup> The expertise of their lived experiences and their leadership in interpreting the context will help researchers understand data patterns, mechanisms that shape these patterns, and the implications for policy interventions. Policies are always informed by and reflect the values of those who design them. Thus, the leadership of community partners in identifying areas for potential collaboration, research design, programme and policy formulation, implementation and evaluation is important.

The success of CBPR depends on the degree to which academic partners who have traditionally wielded power are willing to relinquish it to members of the community. While dimensions of control over the research process are dynamic, there is an inherent power differential between academic researchers and community partners and interrogating power means to acknowledge and relinquish this power. Academic researchers have the theoretical and methodological expertise and resources, including paid time, that are needed to execute the research agenda. However, they might lack experiential knowledge critical to fully understand issues within the community, an understanding that is crucial in informing the nature of data collection and interpretation, dissemination and implications of findings.

Community-engaged health services researchers must also consider how power in and across systems and communities might either foster better health outcomes or reproduce more health inequities.<sup>3</sup> Consider a researcher based in a top tier institution who studies racial inequities in health outcomes using CBPR. That researcher embodies the privilege and status of their institution, which is often in stark contrast with the disadvantages that populations experiencing inequities face. Similarly, the researcher may also have power and privilege from their social class, racial or ethnic background, or other identities and statuses. Individual and institutional power, if not interrogated, might oppress

and exploit communities by limiting their voices, inadvertently prioritizing and asserting the researchers' agenda, hence sustaining social inequities that then produce health inequities.

Our research team has continuously assessed how our statuses as academics, clinicians, community leaders, and our racial and gender identities affect power relations with marginalized persons experiencing social exclusion. This is even more critical for outside researchers.<sup>5</sup> Intersecting identities are just as important. Developing an awareness of what we embody, who we are, and how we present as researchers, whether racially, in terms of gender identity, religion, sexual orientation, institutional affiliation and prestige, political capital and power, matters for our relationships with marginalized populations. We ask how these aspects of our identity determine whose actions or suggestions we choose to acknowledge in the research process and whose we choose to ignore. Common during our meetings are questions such as: "who is not at the table?" When we invite the community and they do join or engage in the ways we hope, we ask: "how are we setting the table?" We made changes ranging from the time and location for focus groups, the type and source of refreshments served during focus groups, as well as participants selecting whether to receive cash cards or gift cards for compensation.

The open and collective reflections about power dynamics enabled us to create space for those without formal power (title or position in an organization) to lead based on their lived experiences in the community. Collective reflections can also help shift power imbalances if during these reflections, partners make a list of the kinds of actions or behaviours that reinforce more dominant voices or exclude others, and that amplify historically marginalized voices. When these power moves are known and recognizable, power can more equitably be shared. As a simple example, we learned earlier on that as researchers, we have the tendency to summarize and re-interpret people's experiences to take away what we want from them. We agreed that participants would write or share a summary of their experiences, expectations, and reflections, sometimes in just one word. If anyone spoke longer or re-interpreted another's experience, including the members of the research team, it was easy to be reminded of the agreement and the dominant voice was abated.

### **Guiding principles for advancing equity**

Researchers must be intentional about shifting power imbalances to advance equity in CBPR partnerships. We discuss three guiding principles: authentic engagement; defining and living values; and

### *Authentic engagement*

Authentic engagement requires learning about people by spending time with them, caring about them and the things that matter to them, affirming all aspects of their lives, seeing them as people with a broad range of commitments, interests, talents, and needs, and building relationships outside of the research endeavor. This means seeking to understand their communities' history, especially as it relates to oppression, genuinely getting to know them, celebrating, supporting, and mourning with them by attending events and occasions that matter, such as funerals and quinceañeras (celebration of a girl's 15th birthday). Although it might be challenging for researchers to "figure out whether and where [to] draw the lines between being researcher and friend or neighbor"<sup>13, p. 267</sup>, building relationships outside of the research process not only increases trust but facilitates accountability.<sup>4</sup> In our experience, knowing what truly matters to the populations we work with and providing friendship and support regardless of the research have really improved our research partnerships.

Experiencing multiple forms of discrimination creates barriers to full engagement for persons with intertwined marginalized statuses. We have encountered situations whereby institutions want to address barriers to health care access among previously incarcerated persons while being hesitant about fully welcoming persons with a history of incarceration into their spaces. We cannot genuinely learn about the perspectives of individuals who we do not radically welcome and who we do not wholly value.

Authentic engagement also means full participation. Persons who belong to marginalized groups identified for our social exclusion study did not just sit in on the focus groups. They facilitated the conversations. All focus groups were facilitated by persons who experienced isolation and felt excluded from care. We learned three things from this approach. First, participants recognized that we genuinely wanted to make this their space, and that they had control of how to share their individual and collective experiences. Second, there were many dimensions of their experiences of isolation that research team did not know about. Third, by facilitating these collective conversations, participant experiences and perspectives were less likely to be reinterpreted through our own lens.

### *Defining and living values*

Research partners must identify and explicitly commit to certain principles or standards of operation and behaviour. Our espoused and lived values often diverge around issues of equitable compensation and

representation for community partners. Living our values of inclusivity and equity with community members as research partners demands parity in compensation for the value community members contribute as context experts in service to their community and to our research institutions.<sup>8</sup> We have been able to provide compensation for focus group participants in the form of cash cards or gift cards of their choice, ranging from \$25 to \$75 per person per meeting. This does not pay for their time but indicates that we value their time. While participant compensation is strongly recommended by funders in the United Kingdom in recognition of the time and expertise provided.<sup>10,19</sup> this is still a contested issue in the United States and Canada because of concerns about persuasion and commodification.<sup>20,21</sup> We have also been able to pay for conference registration, travel and housing costs for our community partner to co-present our work at local and national conferences. We understand that not all community partners might be interested in this but advancing equity befits us to make these options available. Researchers should also explore various ways to value contributions of community members and partners beyond monetary compensation.<sup>8</sup>

Research institutions are often entrenched in the same social, political and economic contexts of the communities they serve. However, institutional values and policies might starkly contrast the values and best interests of marginalized communities. One of the main pitfalls of research that seeks to understand health inequities is the illusion that the inquiry must be value-free and apolitical. But structural and social determinants of health are inherently political.<sup>18</sup> Researchers need to be transparent about their positions on policies that cause harm in communities they partner with. Transparency helps build rapport with communities that we work with, but also positions us to be better advocates for social justice, which is a key element of population health.<sup>22</sup> We recommend researchers who utilize community-engaged approaches to consider their research as a tool for structural change and to explore how collaborative research processes can undo exploitative mechanisms through which social factors and policies affect health.

### *Embracing accountability*

Embracing accountability refers to the availability of processes that help community members to identify and halt practices or behaviours of researchers that might be exploitative. Researchers must create structures that enable community members and partners to influence, negotiate with and hold accountable institutions, including health systems, that shape their wellbeing.<sup>19</sup> One way to foster accountability is to co-

design a checklist that might include issues around researchers' intersecting identities, power, shared values, as well as equitable remuneration for and control over the production and distribution of knowledge.<sup>11</sup>

Our community partner often asked the following question to academic and clinical partners: "How does this contribute to the liberation of our people?" Researchers must be able to answer this question for communities they work with. It pushes researchers to take seriously the concept of CBPR as an instrument of social change. We intend to develop this question further and be able to answer it for every step in every stage of the research process, from identification of the issues to dissemination and implementation of findings.

Another suggestion for accountability is for researchers to connect communities with spaces of resistance. These are entities such as social justice and activist groups and organizations that are critical of practices that exploit marginalized communities. Communities should have access to these kinds of support and to concurrently build resistance while promoting sustainable partnerships and structural change.

## Conclusion

Academic hegemony in CBPR ensures that researchers continue to control the process of creating knowledge to inform health policies. Because these policies are less likely to be truly informed by the experiences of historically excluded communities, inequities persist within marginalized populations that are ironically constantly being asked to participate in research. Researchers must cultivate partnerships that not only provide community perspectives and facilitate recruitment of participants, but that also decolonize the structure, organization and delivery of health services as well as the legislation of health policy. In the context of our work, decolonization means prioritizing the needs of communities experiencing health inequities, and centering research, healthcare delivery, and health policy in the knowledge and experiences of these communities.

Interrogating academic hegemony in CBPR also requires researchers to first understand the complexity of their own identities and positions, and how this shapes the ways by which they catalyze community engagement, how resources are allocated, whose contributions are valued, and how that value is assigned. We must come to terms with the ways that we as researchers are implicated in oppression and in the reproduction of health inequities by constantly examining power imbalances in our relationships with the communities in which we work. Building truly equitable research partnerships is the essence of CBPR and is critical for sustaining community participation in

health systems research that will lead to long-term improvements in population health.<sup>7,23</sup>

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The authors declare that there is no conflict of interest.

## Ethics approval

The authors declare that all the research meets the ethical guidelines.

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