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Commentary

"Research" in Community-Partnered, Participatory Research

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In many underserved communities, "research" is a loaded word that sets expectations of being examined or exploited.¹⁻² This is more likely when data are published but not otherwise shared, such as in a community forum. Research, whether it intends to or not, may disadvantage groups by highlighting problems rather than assets. Research can thus become a symbol of distance between community reality and the "ivory tower," where few mechanisms exist to facilitate community access to knowledge. Academics may view pursuit of knowledge as paramount and in entering research partnerships take such perspectives personally rather than as an expected subject of ongoing discussion.³

That research is a loaded word suggests that it is important to understand the power associated with it. When members of underserved communities are reminded of everyday applications of research, such as seat belts, the sense of alienation the term conveys can disappear. Vulnerable communities can place a high value on processes that advance knowledge, provided there is trust in the researchers and institutions.³

In community-partnered participatory research (CPPR), partners are valued equally and collaborate jointly in research development, implementation, and dissemination.³ Those involved learn to appreciate that knowledge comes in many forms, including data, experience, history, and perception. An authentic partnership must use all means of discovery at its disposal to make progress in understanding how to benefit the community and advance science. To do this, it is important that partners maintain respectful engagement across diverse ways of viewing and gaining knowledge and that they anticipate and embrace the struggles and conflicts inherent in balancing perspectives. The word research, when used in this context, affords an opportunity to build trust.

Merriam-Webster's Online defines research as "1. careful or diligent search; 2. studious inquiry or examination, esp: investigation or experimentation aimed at the discovery and interpretation of facts, revision of accepted theories or laws in the light of new facts, or practical application of such new or revised theories or laws; 3. the collecting of information about a particular subject."⁴

Regarding the third definition, in CPPR it is important to consider how the research issue is chosen and whether it is a matter of community importance; to have transparency about how information is collected and by and for whom; and to ensure that the work develops community and academic capacity to use the research products. Underserved communities particularly value approaches that prevent problems or foster hope.^{3, 5}

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What's this?

The first definition of research emphasizes care and diligence. Although scientists unfamiliar with partnered research may believe that it is not rigorous, such research is based on the expectation that all involved embrace diligence. No one wants sloppy research to inform medical care. The goal is to conduct research that all partners respect as diligent from their own perspective, which can involve compromise and new solutions.⁶

In the second definition, the word "studious" can suggest either diligence or classroom exercises of little relevance. In CPPR, community and academic participants are valued equally, even if roles differ. Academic investigators become part of the community and community members codirect the research, shifting its purpose and process. Limitations of academic experience in the community are balanced by community "PhDs of the sidewalk."

The words "investigation and experimentation" in the second definition can sound neutral or suggest manipulation. In CPPR, the process is one of mutual engagement in a serious effort to improve community outcomes and advance knowledge, in which the full range of methods should be available. Partnered choices of rigorous designs are achieved through 2-way discussions of what various designs offer and how communities engage. Design features such as respect for treatment preferences or wait lists for resources can improve the fit of experimental design and community context, while enhancing the feasibility and meaning of the research. Research of this type is "with" community and academic participants rather than "for" community by academic leaders.⁷

For complex projects using experimental designs, successful implementation requires efforts to support knowledge of methods in some depth maintained by community sources.⁷ Achieving this resource over multiple projects requires a community-owned infrastructure. For instance, a community center of excellence for health research emerged in Los Angeles under the leadership of Healthy African American Families and several academic and funding partners.⁸ Such a center could facilitate community contributions to and uses of research through libraries, trainings, and community engagement events, supported by a community internal review board. Achieving community ownership is challenging under funding priorities that reinforce universities for research infrastructure. There are several examples of sustained partnerships supported by grants and other resources.⁸⁻⁹ Lack of independent funding means that community infrastructure relies on grants managed by academic partners, which is not ideal for true co-ownership.

The second definition of research refers to diverse perspectives on laws and theories, in terms of which are universal and adequately tested, by whom, and for what purpose. Laws and theories once thought universal have been proven limited, as the theory of relativity redefined classical mechanics. Laws and theories are subject to cultural perspectives, including the views of those generating the research and setting the science agenda—a leadership group that has not consistently represented vulnerable populations. Some culturally based theories of importance in underserved groups are not fully accepted as science because they have not been formally evaluated or have been studied only through alternative approaches, such as embracing cultural history or norms.¹⁰ In their work, academic investigators may act as though their way of knowing is more valid than such alternatives, but in their personal lives they may not be so sure. This tension plays out with a different balance in underserved communities, toward personal and collective experience, leading to diverse expectations across groups. If academic and community partners share perspectives as trust is gained, common ground can emerge for concepts and theory that guide research.⁶

In CPPR, researchers seek humility concerning truth and attempt to understand the history and meaning of facts and theories. It is important to remain open to diverse perspectives, even when focusing on design and methods. Efforts to maintain that openness are part of the rigor of partnered research.

This stance of humility pertains to interpretation, referred to in the second definition. Given different perspectives on truth and the difficulty of arriving at shared perspectives given real differences in power and access to knowledge, those involved in partnered research value partnered interpretation. What do the data

mean and to whom? What findings help celebrate community strengths as well as clarify needs, not from a distance but from within the core of the community?

Leveling the playing field, overcoming barriers through honoring diversity, committing to excellence in 2-way knowledge transfers, building capacity for healthy communities while advancing knowledge and sharing the lessons: this is the "research" of partnered research.

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