The Power of Community in “Engage for Equity PLUS” for Strengthening Equity-Centered Patient and Community-Engaged Research in Academic Health Centers

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Abstract

Community based participatory research (CBPR) and patient/community engaged research (P/CEnR) in health have grown rapidly over the last decades. Despite the proliferation of individual collaborative projects, there has been a growing recognition that single projects are insufficient to improve health equity. Improved infrastructures are needed within academic health centers and other research institutes to better support investigators and community members to create and sustain effective research partnerships and projects. This commentary presents a two-year funded effort to transform CBPR and P/CEnR policies and practices at three academic health centers, using the evidence based Engage for Equity tools and strategies from the University of New Mexico Center for Participatory Research. We present a brief overview of the processes and results of Engage for Equity PLUS, with implications for other Academic Health Centers and Universities to take on similar goals of authentic and sustainable engagement.

Keywords: community-based participatory research, community-engaged research, patient-engaged research, institutional transformation, academic health centers, health equity

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Introduction: Relevant Context and Literature

In the last few decades, the rapid growth of community-based participatory research (CBPR) and patient and community-engaged research (P/CEnR) has led to the widespread adoption of participatory principles within community-academic research projects directed at health outcomes (Ortiz et al., 2020). CBPR, as an overall collaborative approach to research, emerged within public health in the 1990s. Grounded in research based on community priorities and strengths towards health equity goals, CBPR also drew from the Global South's social justice participatory research tradition (Wallerstein and Duran, 2018). In 2006, the newer term, community-engaged research, expanded the field through Academic Health Centers receiving National Institute of Health (NIH) funding for Clinical Translation Science Awards (CTSAs) with required community-engaged research cores. Patient-engaged research received a boost with Congressional authorization in 2010 from the Patient-Centered Outcomes Research Institute (PCORI). In this period, patient and community-engaged research (P/CEnR) within public health and health sciences has produced a continuum of engagement strategies, from minimal community outreach to shared leadership (Eder et al., 2023; McCloskey et al., 1997; Sheikhattari et al., 2023). CBPR has extended this continuum to community-led or community-directed research in keeping with its mission to share power between academics and community members (Wallerstein et al., 2018).

Despite the maturation in the field, however, significant gaps still exist in using evidence-based collaborative and partnered research practices for improving health and health equity (Nguyen et al., 2021; Duran et al., 2019; Oetzel et al., 2022). Potentially more importantly, there is a growing recognition that individual projects cannot reduce health inequities alone. For health-oriented research, academic health centers (AHCs) receive the vast majority of NIH funding and, therefore, have a critically important role in creating structured support for equity-based patient/community-engaged research partnerships and projects. While AHCs are primarily located in urban areas, they generally serve large catchment areas, especially in their educational outreach and research portfolios, including specific funding for rural and state-wide research.

Even when AHCs have infrastructures for engagement in place, however, practices and policies typically are insufficient or fragmented across the institution, maintain financial barriers to genuine participation of community or patient organizations, and have variable support from top leadership (Carter-Edwards et al., 2021; Ward et al., 2023). A specific challenge is the lack of institutional commitment to include patient/community leadership in decision-making about research, particularly not engaging patient and community-based organizations in setting institutional research priorities. The inadequacy of institutional support has resulted in continued patient and community distrust of research, producing a pervasive lack of institutional trustworthiness and lack of commitment of communities to research, especially in the willingness of minority populations to participate in studies or in capacities of a research team to
develop culture-centered interventions (Anderson and Griffiths, 2022; Freeman; 2014; Wilkins, 2018; Wallerstein et al., 2019). With years of COVID-19 and increasing recognition of structural racism that minority communities have experienced, the urgency to connect diversity, equity, and inclusion efforts in engaging under-represented communities in research has never been more critical (Fleming et al., 2023; Shelton et al., 2021; Ohmer et al., 2022).

Building on the University of New Mexico’s Center for Participatory Research (UNM-CPR) 17-year NIH-funded Engage for Equity (E2) study that identified partnering best practices, metrics, intervention workshops, and tools to strengthen partnerships at the project level (Wallerstein et al., 2020; Boursaw et al., 2021; Parker et al., 2020; Oetzel et al., 2023), this commentary presents our initial learnings from “Engage for Equity (E2) PLUS,” which was a PCORI engagement award applying E2 tools for change at the institutional level.

To explore the feasibility of institutional transformation, the E2 UNM-CPR team invited three very different Academic Health Centers to participate in the E2PLUS intervention: 1) Stanford University’s School of Medicine and Cancer Institute, 2) Morehouse School of Medicine, and 3) Fred Hutchinson/University of Washington Cancer Consortium. We also had consultation from the University of California, San Francisco’s previous PCORI “ASPIRE” award, which has sought to reframe its engagement structures by directly confronting structural racism (Gewen, 2022; Harrison et al., 2022), and from Campus Community Partnerships for Health.

Among the E2 PLUS institutions, Stanford represented an elite private university focused on basic science research with a growing clinical research agenda. Yet, their clinical care services were often inaccessible to communities experiencing marginalization, therefore impacting their ability to develop trust among communities for research. Pediatrics has been an early-adopter exception that integrated its ability to serve Medicaid patients with a greater capacity for engaged research. With an opposite reputation as Stanford, Morehouse School of Medicine is a historically black medical school with a five-decade history and mission built on health equity, which one leader simply stated was an integral part of “their DNA.” Community-engaged research capacity was embedded with long-term funding for the Prevention Research Center (PRC). This funding provided grounding for their own Morehouse Model and a solid base for institutional engagement practices (Braithwaite et al., 2020), but resources were fewer and less distributed throughout the institution. In the middle of the three, related to engaged research structures and practices, the Fred Hutchinson Cancer Center had a long history of well-recognized individually led CBPR but had a newer Office of Community Outreach and Engagement established because of recent NCI-Comprehensive Cancer Center requirements. As the E2 PLUS work started, conversations were in progress to merge Fred Hutch with the elite, well-funded public research institution, the University of Washington, and with the Seattle Cancer Care Alliance and Seattle Children’s Hospital as a new Cancer Consortium, opening strategic possibilities. While all institutions had Clinical Translation Science Awards with
community engagement centers, the UNM E2 team worked across multiple centers and institutes.

**Methods**

Within these diverse contexts, our UNM Engage for Equity PLUS intervention started by developing champion teams as change agents, consisting of 5-7 investigators and half patient/community partners (Sanchez-Youngman et al., 2023). While the UNM E2 team worked separately with each institution over the two-year period, we brought the three champion teams together in quarterly Zoom meetings as a community of practice to share learnings as we progressed. Because E2 PLUS was implemented during COVID, all intervention activities at each site took place online, with a final face-to-face meeting of champion teams in Albuquerque at the end of the two years. See Figure 1: E2 PLUS Engagement and Data Collection Activities.

![Diagram of E2 PLUS engagement and data collection activities](image)

**FIGURE 1.** E2 PLUS engagement and data collection activities

In the first year of the E2 PLUS intervention, the UNM-CPR team facilitated monthly champion team meetings, held two sets of Zoom workshops for 30-35 diverse stakeholders (larger group of patients/community members, investigators, and top leaders) applying E2 tools, and collected survey and interview data of barriers and facilitators for the champion team to use as advocacy to top AHC leaders.

In the first workshop, participants identified their previous history of engaged research by creating an institutional “River of Life,” a visual document of their trajectory with community and patient partners, ending up with the existing status of engaged research (Sanchez-Youngman and Wallerstein, 2018). The UNM-CPR E2 team conducted 3-4 top leader interviews and two community/patient and investigator focus groups via Zoom. It piloted an internet-based institutional multi-stakeholder survey (IMSS) (n=30-35) of institutional climate, practices, policies, and norms. These data, including the River of Life in the qualitative themes, were
analyzed by the UNM team by site, with analyses brought to champion team meetings for co-
interpretation and further analysis. In the second workshop, the UNM E2 team presented the
combined data to the larger group and engaged participants in using the CBPR Model as a
Visioning Tool to identify institutional targets for change (Parker et al., 2020).

In reflections with champion teams and dialogue at the second workshop, the data illuminated
important tensions within each institutional context, and catalyzed the formation of working
groups to seek changes from top leaders in policies and practices that would better support
equity-centered, community/patient-engaged research.

Results

While the AHCs started at different levels of capacity and readiness, qualitative data produced
parallel, yet distinct tensions. Stanford participants identified their institution as a national
research leader that historically has focused on service to address local health equity issues, with
few and fragmented community/patient engagement resources that are rapidly growing, a
research bureaucracy that can be challenging to navigate, and a lack of consensus of what
constitutes authentic community representation. While CBPR was seen as a fast-emerging
strength with meaningful investigator commitment and new top leader interest, community
partners wanted bidirectional partnerships and structural change rather than just “checking the
box.”

Morehouse School of Medicine, on the other end, a nationally-recognized engagement leader
with strategic long-term community/patient collaborations, succeeded at receiving long overdue
federal funds during COVID for community-centered public health, e.g., the National COVID-
19 Resiliency Network, RADx® Underserved Populations, and from the Community Engaged
Alliance (CEAL) Against Covid. Participants still stated they faced limited resources, with few
experienced faculty assuming the burden of CBPR. While the PRC Community Coalition Board
governance structure was recognized for its community-driven power, respondents stated the
need to broaden internal engagement and outreach to more diverse communities and to
disseminate their community research governance model. They wanted to expand their ability to
formalize partnerships aimed at transcending rather than tokenizing diverse engagement.

The Fred Hutch/UW Cancer Consortium participants expressed less alignment, with faculty and
leaders believing there was good forward movement. At the same time, patient advocates and
community members felt there was still a long way to go to engage patients and the community
in research. Many respondents to the data collection stated that they experienced P/CEnR as
“recruiting minorities in research” versus building community/patient voice and influence
throughout the research process.
In all sites, qualitative data highlighted individual faculty members as P/CEnR resources while lacking institutional structures and systems for sustained patient/community workstreams (including templates, resources for specific research issues, and sufficient training for investigators and communities/patients). Barriers in financial systems were especially noted in terms of long delays in post-award contracts to community partner organizations. Community and patient members in their specific focus groups and within champion team dialogues also insisted that they not be taken advantage of, i.e., placed on grants without consent or having only a few community or patient advocates overburdened to be on every community/patient advisory board. They have insisted on the importance of sustainability each step along the way.

Survey responses of investigators, community members/patients, drawn from those involved in community advisory boards or on CBPR or P/CEnR research teams, and top leaders generally agreed with qualitative findings of insufficient structures and policies. Though not completely overlapping, many survey respondents participated in the two workshops and provided feedback in interpreting preliminary data analyses. Importantly, a high percentage of survey respondents stated they lacked knowledge around engagement and equity practices and policies at all institutions, uncovering the need to enhance communication while working on specific goals.

By reflecting collaboratively on their data and the exposed tensions, each champion team identified their working groups and change targets. Stanford’s champion team identified three goals: 1) to adapt Institutional Review Board procedures to CBPR’s unique context; 2) to streamline post-award procedures to ensure that community partners receive timely payments; and 3) to build CBPR internal capacity among community partners. Working groups were able to build on growing equity initiatives from leaders, such as the Stanford Medicine Commission on Justice and Equity (Commission, 2021), and benefited from their Maternal Child Health Research Institute Symposium, supported by Stanford’s School of Medicine and CTSA leadership in 2022 to bring in national equity-based leaders. Evaluations showed new documentation of specific IRB barriers for CBPR projects, proposed changes to workflows to efficiently obtain research approvals and timely community payments for these projects, and galvanized support for CBPR staff hires and offices.

Morehouse identified goals for system-level improvements to strengthen P/CEnR, including greater recognition for community/patient partner research navigation systems with formal agreements, and has pushed further, with the promotion of strategies to improve capacities of community/patient organizations to independently acquire grants central for addressing their priorities. The Fred Hutch/UW Consortium’s champion team, supported by the Fred Hutch Office of Community Outreach & Engagement, accomplished new strategies to increase the participation of under-represented patient and community groups at multiple levels. These successes have included the Consortium’s External Advisory Board welcoming its first-ever patient advocate members, new resources for a proposed Office of Patient Engagement,
expansion of P/CEnR training, and recognition of the need for a big tent for anti-racism efforts across the Consortium.

Discussion and Conclusion

In summary, this PCORI engagement award showcased the feasibility of implementing E2PLUS strategies with a small group of diverse AHC institutions to maintain interest and actions across the two years. With coaching and support from the E2PLUS UNM team, all institutions have formalized and benefited from dedicated champion teams and from having specific targets for change. Key strategies that have shown effectiveness include: ongoing coaching so that champion teams develop cohesion as facilitative leaders of the process, multiple opportunities for iterative reflective dialogue leading to actions, use of mixed-methods data for advocacy to top leaders, and commitment to high-level patient/community involvement in the champion teams and all stages of the intervention. Engaging top leaders early on was essential in creating new windows of opportunity for change actions. Through their interviews and hearing presentations of the aggregated data in workshops or separate meetings with champion teams, top leaders became more responsive to strategies to address financial and administrative barriers. Statements from community members and patients were particularly important about their challenges to engage without sufficient resources or commitment. Leader responsiveness to providing new resources, such as additional staff, enhanced structures for patient engagement (rather than just for community engagement), or even seeking more information about the challenges, provided recognizable benchmarks of progress towards institutional transformation.

Community of practice dialogue among the three champion teams, solidified during one face-to-face meeting at the end of the award period in the spring of 2023, were also helpful in sharing challenges, learnings, and inspiration. Separate meetings among community members and patient partners from the three institutions were also important for their co-learning as well as maintaining the strength of their advocacy. Together, these intervention strategies, within and across each research institution and their communities and with other sites, could be helpful to other institutions seeking to build long-term commitments to CBPR and patient and community-engaged research for health equity goals. The UNM-CPR E2 team is pursuing funding to extend our learnings from the engagement award and to test the intervention among a larger group of academic health centers to understand better how a greater diversity of conditions of institutional capacity, size, and readiness interact with distinct patient populations and communities to support or inhibit these changes.

While institutional changes were the E2PLUS focus, the external context remains critical. COVID created more opportunities for community-engaged funding, yet, long-term, a shift by funders towards primary support for community and patient advocate organizations is essential. New language on building community power is circulating (Iton et al., 2020; Ponsforth et al., ...
2021; Sanchez-Youngman et al., 2021), recognizing that reducing disparities cannot come from institutionally based research projects alone (no matter how engaged). As expressed by many of the patient and community members who were involved in champion teams, they want to be recognized for their existing capacity, with strategies to further strengthen their capacity to lead research and make their own decisions of how and with whom they partner. This shift in thinking about how academic institutions and research can support community and patient advocates and their organizing initiatives to improve health conditions may be most helpful for promoting the structural changes in racial and social inequities needed to authentically advance health equity.
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