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Critical Reflections on This Historical Moment for Community-engaged and Participatory Research

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Submitted 5 April 2023, revised 27 July 2023, accepted 21 August 2023.

Research and training institutions, public health and health care systems often lack sustained, effective engagement with communities. This hinders the ability of scientists, researchers, and health care providers to examine their unconscious biases and improve their capacities to collaboratively work towards reducing health inequities. The coronavirus disease 2019 (COVID-19) pandemic starkly exposed, once again, the depth of the racial and social inequities in morbidity and mortality across individuals and communities. It reified systemic racism, with ongoing police shootings further highlighting the deeply entrenched anti-Black racism and how little has changed since the first slave patrols evolved into our system of policing. It further exposed the support for policing from a system of justice that effectively sustains racial separation accompanied by inequality of access to services. Social biases are further evident in the consistency of data by group regarding racial profiling and traffic stops, involvement with the legal system and incarceration rates.

Although racism touches every group at some point in time, its genesis in the United States validated Native American genocide and African chattel slavery. As Native Indians were relegated to reservations, slaves remained a visible part of everyday America. Visibility has produced an embedding of anti-Black racism into our laws, policies, practices, history and media, resulting in a massive imbalance in the distribution of community level life and health affirming resources and opportunities.

Confrontations regarding rights and the potential for silencing populations most adversely impacted once again occupies the public conscience. Current legislated actions to restrict voting rights, to censor and/or ban books from schools and libraries that address race and gender orientation and identity differences, and debates about academic freedom and first amendment rights in institutions of higher learning and the media, resonate with post reconstruction action to rescind the rights of freed Black Americans to citizenship through repressive Black Codes/Jim Crow laws.[1,2] As we chart a way forward, the proactive response of many communities of color during COVID and the response to the brutal police murder of George Floyd, among so many other often unarmed Black people, remind us of the central role of community engagement for raising awareness and for collaboratively addressing the needs and priorities of our most marginalized.

Despite world-class scientific credentials and accomplishments, our leading research and academic institutions often do not know how to meaningfully engage with local communities or simply don't understand the importance of doing so; many departments of health are similarly challenged to genuinely reach and engage diverse local populations. The commitment to engagement must address identity concordance at all levels of the workforce, including research, administrative, financial, instructional and clinical staff. A strong evidence base now demonstrates that community engagement and community-based participatory research (CBPR) can improve the "rigor, relevance and reach" of research[3] and positively impact multiple system and individual health outcomes.[4–7] The improvements are multidimensional and accomplished through the unique insights and nuances community partners bring to understanding the root causes of health problems, illuminated by past and current understanding and exposures to varied social contexts. Our institutions need to expand their capacity to benefit from collective community wisdom, lived experience, and cultural strengths, if we are to reform current systemic approaches that too often restrain real solutions.

Unfortunately, universities and academic medical centers typically are not structured to support such work; institutional, financial and administrative processes and policies all pose significant barriers. These include, for example, an inability to pay community partner organizations in a timely fashion or establish infrequent payment schedules for community member participation; the institutional capacity to set priorities that allow institutions to maintain control over infrastructure. There is evidence of insufficient support for and engagement of community investigators in institutional review boards, a lack of adequate training in engagement and participatory methods and practices, and a legacy of structural racism in hiring and retention of faculty who serve on those boards. In addition, the predominance of fee-for-service payment models within the health care sector continues to discourage investment in disadvantaged communities, ensuring those with the poorest health and the greatest need will have limited access to services and benefit. Policies and practices have also too often failed to develop the community capacity, infrastructure, and trust that serves as a foundation for collaborative research.[8–10]

Numerous historical narratives recount egregious research ethics, exacerbating community distrust of research, medicine and science. Black males in Tuskegee denied treatment for syphilis (1932–1972),[11] Mexican women immigrants in California sterilized without consent (1960–1970),[12] and Native Americans in Arizona whose DNA was misappropriated (2003),[13] are not just news events but historical sources of collective and personal trauma.[14] Trauma, fueled by a legacy of unethical behaviors and substandard health outcomes, is summarized by the Association of American Medical College's first principle of trustworthiness: "The community is already educated; that's why it doesn't trust you."[15] There are alternatives. An exemplary *promotores* study, which engaged Spanish-speaking women online during the pandemic, enabled participants to learn about hereditary breast cancer and family history risk.[16] This effort improved awareness of BCRA breast cancer risk gene variants among participants while highlighting an unacceptably low rate of women's access to the use of mammography, cervical and colorectal preventive testing. This is but one example from an impressive record established by CBPR and other forms of community-engaged and participatory research, which this journal has helped to publicize, a record of achievements and shared benefits which needs to be more broadly recognized and nurtured. With a plethora of scientific studies showing greatly improved health outcomes when community partners, faith-based institutions, and other trusted community resources and individuals are involved, the challenge now is for academic, public health and health care institutions to reinvent themselves, becoming more trustworthy as they engage communities across all levels of research and practice.

Increasing the institutional capacity for engaging communities of color, rural, and other vulnerable populations throughout the research process has been a recognized scientific imperative among many institutes and centers within the National Institutes of Health (NIH). The National Cancer Institute, the National Institute of Environmental Health Sciences, the National Institute on Minority Health and Health Disparities, and the National Center for Advancing Translational Science exemplify how NIH entities and scientific communities have intensified work in partnership with communities to advance science by developing both new and improved clinical and biopsychosocial therapies and outcomes. These efforts include engaging a culturally and linguistically diverse medical, scientific, and public health workforce that can build on concordant identity characteristics and

shared cultural and social understanding to contribute to trust building. Equally important are opportunities for individuals from communities of color and other marginalized groups to participate in research that transcends contexts in which the data primarily informs narratives of deficiency and disparity. The NIH supported the *All of Us* Research Program to enhance the personalization of medicine provides a current example, noteworthy for both its focus on participant diversity and on allowing participants to manage how they participate and the data they contribute.

To meet this scientific imperative, a petition signed by 500 academics and community members was sent to the White House in January 2023 encouraging President Joe Biden to appoint a new NIH Director who understands the importance of listening to community priorities and strengths, engaging diverse populations and perspectives, and educating the public. In April 2023, it was announced President Biden will nominate Dr. Monica Bertagnolli, currently the Director of the National Cancer Institute, and only the second woman to be nominated to the top NIH post. A breast cancer patient herself, Dr. Bertagnolli is an oncologist and a well-known patient-centered cancer researcher.

But leaders do not act in a vacuum, which makes it incumbent upon our federal agencies, research universities, schools, colleges, foundations, and communities, to demonstrate their support for a candidate with a demonstrated understanding of, and belief in, the power and potential of community-engaged and patient-engaged research for studying, sharing, discussing, and acting on many of our most pressing health problems, including inequity in all its physical and psychosocial manifestations.

Additionally, federal agencies, research and academic institutions must better prepare themselves to support teams composed of diverse individuals and ways of thinking.[17] The expanded use of listening sessions that augment requests for written comments on federal rulemaking illustrates a commitment to learning through engagement and inclusion strategies.[18] A commitment to diversity in all its forms enhance inquiry about physical causality and psychosocial processes and meanings that can impact our deep racial and health inequities: A commitment to diversity across the institutions participating in the national research enterprise will make more likely the translation of findings into actionable, equitable, valued change.

Institutional change is rarely easy or linear. The Council of Public Representatives, developed in 1999 to advise NIH leadership was subsequently disbanded, even as NIH Institutes and Centers expanded their support for community-engaged and CBPR. Concerns have been raised about CBPR being co-opted with the infusion of "tourist researchers" whose study designs give the illusion of partnership, while leaving unaltered hierarchal institutional processes.[19] Such research implementations not only subverts the intent of CBPR but concurrently amplifies a source of community mistrust.[9] Diligence must be maintained to ensure that community-engaged and participatory approaches retain their partnered and action-based intent, through actions such as returning data to communities for their ownership and translation and using research successes to help craft health-enhancing policies, programs, and practices.

Fortunately, several recent examples of progress to reintegrate community engagement at a high level may be found, including the Community Engagement Alliance, the Rapid Acceleration in Diagnostics in Underserved Populations to address COVID-19 testing and testing technologies, and the Researching COVID to Enhance Recovery grants. Although important, even these new engagement initiatives continued to direct funding to institutions and not communities. Emulating an emerging trend of foundations directing funds to communities, the NIH has created its first truly transformative commitment to community engagement through the Community Partnerships to Advance Science for Society, where community-based organizations will actually lead research partnerships to address health equity. The change in community power over the control of resources belatedly builds on the Native American Research Centers for Health NIH initiative where tribes or tribal entities are the principal investigators, placing priority on building local capacity and infrastructure to lead research while working with academic-based researchers.

NIH, academic researchers and their institutions, could also benefit from the recent recognition by the Robert Wood Johnson Foundation and The California Endowment regarding the importance of "community power" to make a genuine difference in health equity outcomes.[20] Multiple actions can support community power in CBPR and community-engaged research partnerships, such as promoting community decision-making or governing boards (more than advisory committees), community organizations leading research efforts, shared budgets for communities if academics are leading, data ownership and publication

agreements, and other forms of structural governance agreements.[21] Tribal Institutional Review Boards have also exemplified the importance of community benefit, beyond individual risk/benefit ratios,[22] along with other community ethics concerns.[23]

These strategies, which can be enhanced by support of the new NIH director, showcase how to integrate and maintain a strong commitment to scientific rigor and community engagement expertise. Recognizing the value of community input within processes of knowledge production, the director and other scientists may also strive to articulate the essential role of cultural humility and critical reflection through assessments of engagement with community perspectives within research labs and teams. Such leadership could inspire community-based and translational researchers, in part by helping support as part of its mission, authentic community-based and participatory research with its proven track record for building community trust, promoting systems change and contributing to improved health outcomes.

This is no easy task. The NIH, medical and academic institutions, reflect a cultural predilection for dissecting experience and fragmenting knowledge into siloed and seeming independent entities. Specialization further informs a reductionist understanding of expertise and the institutional structures for managing it. These same institutional structures become a weakness when they hinder reconfiguration of knowledge domains and the exploration of novel interconnections and interdependencies. Additionally, the custom of cloistering research findings and new knowledge in hard to access publications, many with economic roadblocks through expensive subscriptions, maintains barriers to community access and scientific understanding.

A science of community engagement challenges us to move beyond schools of medicine, public health and departmental specializations, to create a dialogue that includes interdisciplinary expertise along with epistemological approaches derived from community members, patients and caregivers. Alternative forms of expertise based on lived experience and deep community and cultural knowledge must be respected and accepted for the development of community-engaged team science. In addition, team science requires that academic institutions recruit and train scholars from BIPOC communities: Diverse teams improve our potential to reach often "unseen and unheard" minoritized and marginalized communities.

Without openness, involvement, and transparency, and despite efforts to address the often deep and understandable fear of systemic biases, many minoritized communities will likely remain distant from medical care, research, and the public health workforce. Without engagement, efforts to achieve evidence-based reductions in morbidity and mortality involving cancer, emerging infectious diseases, and chronic disease management and prevention, will be diminished, or even futile. Hampered too will be our ability to more effectively and consistently translate research findings into actionable changes in programs, practices and policies that produce health equity. Dialogue among trusted partners provides a proven strategy for overcoming the politicization of science and the dangers of action based on misinformation or opinion. Dialogue and open, free community access to published science findings can facilitate transparency in making clear what research can and cannot do, and how science can inform clinical practice and public health policy.

Current actions to foment community engagement and transform partnered research and programmatic activities to pursue greater equity include the following.

1. Involve and listen to community voices in developing training for health and public health researchers and future researchers. Within the training, students must confront stories of abuse, particularly those involving medical and public health personnel within communities of color in the name of science, exploring how historical and contemporary examples of interactional and outcome inequities and disparities may be eliminated in the future. Explorations regarding the hidden curriculum indicate the need for faculty and mentors to examine their own sense of professional identity, social networks, values, behavioral norms, and unconscious biases at play in the learning environment, if they are to engage their trainees and mentees equitably.[24,25]

2. Create an infrastructure to sustain involvement of community voices and perspectives in developing training, in implementing policies and practices regarding research ethics, and in the review of community-engaged and participatory research protocols. Expanded community infrastructure has the potential to transform academic institutions and their relationships to communities by creating the potential to realize benefit from both the new knowledge generated by

research and from the increased community involvement in research implementation that may entail material development, education, training and skill development that continue to serve communities.[26]

3. Restructure research funding mechanisms to increase or equalize decision-making power and support the infrastructure necessary to conduct research within community contexts. Efforts should be made to align this infrastructure with the production of benefit from improved access to and the delivery of standard of care clinical services; synergies between research and clinical care facilities and services should be explored.

4. Examine institutional research management roles to refine the understanding of and effective support for community partnerships that includes development of infrastructure within communities, both facilities and personnel, to support research, translation of evidence into practice, and access to health services.

We could continue doing what we have been doing, expending significantly more financial resources than other nations while producing comparatively poor public health outcomes. We could continue talking about and demonstrating how community-engaged and participatory research increases the potential for the entire population to benefit and in particular communities who have historically experienced marginalization and oppression. Or we could change by engaging community voices and perspectives, respectfully and with curiosity, and further acknowledging that some community perspectives possess epistemological validity.

We must create authentic opportunities for both dialogue and action with communities about a broad range of topics that enable improved public understanding and authentic participation in decision-making. Because we know that bringing community expertise to research and research to community through respectful and equalized engagement makes possible more patient and community-centered research into diseases and cures and improved community awareness of prevention, screening, and diagnosis, we advocate for a science of community engagement predicated upon system and policy change. We sincerely hope the new NIH Director and leaders of our research institutions will understand and embrace emergent realities; that we use our expanded awareness of structures and practices which currently maintains inequities to advance systems change; and that we move forward collectively, improving both the science of medicine and public health in the process. Enriched by community participation, knowledge, collaborative action, and a shared understanding of what is genuinely significant, we can refine our capacity to translate research into improved outcomes that contributes to racial, social, and health justice.

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