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Advancing Community-Based Participatory Practice in Public Health

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Abstract

This policy statement fills a gap identified by the Joint Policy Committee to address persistent and widening health inequities in the United States by advancing community-based participatory practice. Despite high health care expenditures, the United States continues to underperform in health outcomes relative to other high-income nations, with recent alarming drops in life expectancy. The systems and structures that perpetuate these widening health inequities necessitate comprehensive public health strategies that encompass meaningful collaborative engagement between communities and public health practitioners. This policy statement advocates for widespread adoption of community-based participatory practices throughout the public health field, emphasizing the inclusion of community members in every stage of the public health process. This includes incorporating the lived experiences of community members as a valuable form of expertise, developing action-focused feedback loops to refine interventions, and ensuring data equity to address systemic biases. The statement also underscores the importance of community-based participatory research as a mechanism to meaningfully engage communities in addressing critical gaps in information about public health challenges. In addition, it urges the field to move toward power sharing and collective control in decision-making processes, including the formation of community research review boards to ensure ethical and community-aligned research practices. The overall aim is to foster a more inclusive, equitable, and effective public health system that genuinely addresses the needs and priorities of

all communities, particularly those historically marginalized and disproportionately affected by health inequities.

Keywords: health equity; community participation; community health planning; community-based participatory research; health services administration

Relationship to Existing APHA Policy Statements

- APHA Policy Statement 200412: Support for Community-Based Participatory Research in Public Health
- APHA Policy Statement 202210: Reimagining Public Health Leadership for Health Equity: Moving Toward Collective and Community-Centered Applied Practice
- APHA Policy Statement 20224: Advancing Environmental Health and Justice: A Call for Assessment and Oversight of Health Care Waste
- APHA Policy Statement 202115: Noise as a Public Health Hazard
- APHA Policy Statement 20218: Call for Urgent Actions to Address Health Inequities in the U.S. Coronavirus Disease 2019 Pandemic and Response
- APHA Policy Statement LB20-04: Structural Racism is a Public Health Crisis: Impact on the Black Community
- APHA Policy Statement LB20-02: Health Inequities in the U.S. Coronavirus Disease 2019 Pandemic and Response
- APHA Policy Statement 20197: Addressing Environmental Justice to Achieve Health Equity
- APHA Policy Statement 20182: The Environmental and Occupational Health Impacts of Unconventional Oil and Gas Industry
- APHA Policy Statement 20171: Supporting Research and Evidence-Based Public Health Practice in State and Local Health Agencies

Problem Statement

Social determinants, systems, and structures are associated with long-standing health inequities.[1,2] Despite decades of attention to health inequities in the United States, widening gaps in health-related outcomes persist.[1] Prior to the COVID-19 pandemic, life expectancy in the United States lagged behind peer nations; the additional drop following the pandemic is staggering, with available data showing the greatest losses experienced by American Indian and Alaska Native, Black, and Latine populations.[3] Beyond COVID-19, health disparities across structurally marginalized groups such as the LGBTQ+ (lesbian, gay, bisexual, transgender, and queer) community, immigrants and refugees, people experiencing homelessness, and communities of low socioeconomic status have persisted and, in many cases, worsened, because of intersecting mechanisms based in sociopolitical power and privilege.[4] Maintaining this inequitable system is costly: In addition to unmeasured human capital losses due to preventable illnesses, the United States consistently ranks among the lowest of high-income countries for health-related outcomes, despite reporting the greatest per capita expenditure.[5] Also, recent studies demonstrate diminishing trust in public health and the scientific community.[6,7]

Communities unjustly impacted by health inequities possess unique skills, strengths, and resources that have allowed them to survive while being structurally marginalized. Often bucketed under the umbrella term “resiliency,” public health has embraced the idea of incorporating community assets as a public health strategy for more than a decade.[8] Substantial evidence indicates that structural determinants of social, economic, and political marginalization contribute to persistent health inequities.[9] Shared public health ethics and morality require that we address social determinants, systems, and structures that perpetuate poor health. Active and meaningful participation by structurally marginalized communities is essential to this process. Meaningful community participation is effective in reducing health disparities and fosters community development. [10–12]

In 2004, APHA recognized the importance of community-based participatory research (CBPR).[13] APHA's policy, building from Barbara Israel's foundational work and the evidence base that has emerged since, supports the effectiveness of CBPR approaches linking participatory research to effective practice.[11,14] There is a growing need to adopt participatory practices developed for CBPR outside of the research context and more broadly throughout public health practice. Here this is referred to as community-based participatory practice (CBPP). However, CBPP can be difficult to honor, in part due to structural, institutional, and systemic barriers. These barriers can contribute to misunderstandings or misalignments of goals, benefits, or processes that strain relationships among communities, researchers, and practitioners.[11] As a result, relationships must be carefully established, nurtured, and maintained over time, in an atmosphere of mutual dialogue and respect, to maintain (or regain) mutual trust.[11] Real ethical concerns about privacy and confidentiality create complexity, while conflicts of interest between a community and researchers or practitioners can halt progress and lead to harm.[11]

Despite these challenges, recent and ongoing efforts to address systemic drivers of health inequities have resulted in new mandates for the public health community.[1] There is growing recognition that CBPP offers critical insights for improving public health practice as well as research.[14–16] Structurally marginalized communities have generations of experience navigating the systems that perpetuate harm. This lived experience, paired with the increasing inclusion of people from structurally marginalized communities in public health systems and leadership, creates opportunities to improve public health practice toward achieving health equity.

Evidence-Based Strategies to Address the Problem

While CBPR primarily focuses on research processes, CBPP encompasses a broader range of participatory activities that include, but are not limited to, research.[17] While some community-based approaches, notably community health needs assessments, are widely accepted in the field, they are often completed with limited or no meaningful community engagement.[18] To truly build toward CBPP, institutions can incorporate increasing levels of shared leadership and participation progressively over time to build trust and the capacity for CBPP.[12] This policy statement does not intend to curate an exhaustive list of evidence-based strategies but, rather provides feasible examples of different depths of CBPP. Engagement with the public in pursuit of health equity requires a tailored approach with each community to earn trust and build partnerships.[2,19–21] For the purposes of advancing health equity, this statement focuses on evidence-based strategies that involve active multidirectional participation in public health practice.

Recognize that lived experience is expertise

Ample evidence affirms the value of community input to public health. Community members have unique knowledge about the social and environmental factors contributing to their community's health, first-hand experience navigating health-determining systems, knowledge of what interventions and policies have and have not worked for them, and experiential insight into why.[12,20,22] Given the history of unethical practices and outright discrimination based on income, insurance status, race, and other factors, trustworthiness must be demonstrated by public health practitioners.[23,24] Building trust is required for any longer term investment, particularly in communities accustomed to extractive, short-term engagements.[21] Community members and community-based organizations often serve crucial public health roles as primary responders to local needs left unmet due to systemic failures, gaining unmatched wisdom that can greatly inform and improve public health actions.[19,25]

Acknowledging lived experience as expertise akin to educational or professional qualifications requires the public health field to challenge elitist notions of "expertise."[26] This may engender resistance from public health teams, their supervisors, and others whose expertise is recognized by dominant groups (e.g.. those with academic credentials and other privileged groups) but who lack lived experience.[27] It is the responsibility of the public health community to ensure that community expertise is meaningfully and sustainably integrated into public health activities.[20,27] This responsibility includes acknowledgment of the role public health institutions have played in eroding the trust of structurally marginalized groups and active restitution for those trust-destroying practices.[24,27,28]

Evidence supports the advantages of integrating lived experience within public health systems (e.g., peer services, promotores), including clinically significant benefits such as reduced need for costly hospitalizations.[20,22,29] Services provided by people with lived experience must not be used to offset labor or budget shortages with lower cost services but be integrated as complementary services that improve quality throughout the system. Lived experience must be valued: Financial compensation should be comparable for services typically requiring academic and professional credentials.[30] Investing a portion of the resources currently used to fund management consultants to support community-based expertise can result in more appropriate and sustainable public health solutions centered on community benefits.[31] In addition to financial compensation, there are opportunities to continue engaging communities that have provided expertise and information, such as using institutional ties and influence to support community action and advocacy related to health challenges.[20,27,30]

Incorporate place-based and environmental justice approaches

"Place" is a long-established social determinant of health, with widespread development of place-based approaches to achieving health equity.[32,33] In the United States, racist practices and policies have segregated urban and rural geographies, shaping determinants of health and creating geographic health disparities. Public health practitioners using placed-based approaches should consider the interaction of community diversity and geography in the public health process.[29] Communities may self-define according to geographic boundaries that differ from administrative boundaries tied to funding streams, health data aggregation boundaries, or government catchment areas that control upstream policies.[12,32,34]

Geographically defined communities include members with intersecting identities. There is no single set of best practices that applies to all different community makeups; however, a few universal strategies have emerged.[1,32] Public health practitioners must honor differential relationships and power dynamics at play within participating communities and with the public health community; this requires reflexive self-examination by the public health team and the development of multilevel participatory strategies.[1,32,35]

CBPP activities are often designed with a geographic component to advance environmental justice, a social movement based on the principle that environmental risks, protections, and benefits should be distributed equally to all people, with the recognition that "dominant political and economic structures disproportionately locate environmental pollution and other sources of health risk with communities in poverty and communities of color."[35] Because environment is a critical determinant of health, public health practitioners must address and acknowledge "environmental justice communities," which are usually geographically defined.[2,27]

Develop action-focused community feedback loops

Feedback mechanisms that result in corrective action and improved interventions have long been used to identify and address implementation challenges; instituted globally in resource-limited and emergency settings, their feasibility is well established.[36] Tools that highlight the value of integrating action-focused community feedback loops, such as health equity and/or racial equity impact assessments, are recommended in the United States given pervasive health inequities according to race and ethnicity.[20,21] Feedback mechanisms should be context and community specific, taking into account both community acceptability of and familiarity with the mechanism; a variety of feedback mechanisms may be required. Expectations for community members and public health practitioners should be jointly established up front, with predetermined check-ins to evaluate performance and implement necessary changes. Feedback mechanisms must necessitate responsive action, including acknowledgment of received feedback and appropriate communication of actions taken.[32]

From an intervention perspective, evidence-based practices (EBPs) are recommended by funding institutions due to scientifically backed results; to align with the evidence, such programs are implemented as is to ensure fidelity to the model. However, studies supporting EBPs often have small sample sizes from culturally, linguistically, and/or socioeconomically diverse communities, limiting the generalizability of the evidence base.[20] If the evidence base supporting EBPs has not been fully established for the populations being served, more information is needed to ensure effectiveness beyond acceptability and feasibility.[37] Given the high costs of EBPs, the potential for inefficient investments in programs that are not well evidenced for the communities experiencing health inequities must be considered. Action-focused community feedback loops can detect potential inefficiencies of EBPs within service communities and redirect resources more effectively for greater impact.[20]

Address gaps in knowledge through CBPR

Participatory research approaches such as CBPR and youth participatory action research are built on an understanding that more traditional, researcher-driven approaches to building knowledge often exclude the critical knowledge and insights of those most adversely impacted by social, economic, and political inequities.[14,38] Systemic inequities affect the information generated, knowledge gained, and ways in which data are collected and used. The resulting understanding of public health challenges is partial and distorted. This directly impacts resource allocation, community trust in public health systems, and uptake of public health activities. If systemic inequities are to be meaningfully addressed, members of disproportionately affected communities should be engaged in identification of research questions, decisions about data needed to understand public health phenomena, interpretation of findings, and decisions about actions based on study findings.[27]

CBPR is a partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process, including leadership and decision making about how to apply research findings in public health practice and to support relevant policy changes.[10,14] All partners contribute their expertise and share responsibilities and ownership of projects designed to enhance understanding of a given phenomenon as well as integrate the knowledge gained with action to improve the health and well-being of community members. With roots in emancipatory movements for equity in both the Global South and Global North, CBPR is a feasible and powerful approach that leverages multiple methods.[10,14,27] These include quantitative methods (e.g., traditional, short-response surveys; validated scales; and use of administrative data sets) and qualitative methods (e.g., in-depth interviews with numerous opportunities for substantive, personal, and other insights; focus groups; and visual and narrative methods such as photovoice and storytelling) that can fill gaps in public health knowledge, focus research on community priorities, identify barriers to community wellness, create community-specific solutions to health challenges, and offer benefits to the participants themselves.[14,27,39,40]

To advance and improve CBPR efforts, public health investments that amplify the capacity of structurally marginalized communities to initiate and lead formal research activities on issues that directly impact them are critical. Building career ladders for the workforce by investing in training and capacity building for people with lived experiences of inequities to lead research activities is one approach.[20,41] This will not only benefit the expansion of knowledge required to advance health equity but sustain and strengthen the field of public health over time.[42] For example, the National Institutes of Health Community Engagement Alliance (CEAL) program built rapid new partnerships between researchers and members of hard-hit communities facing the COVID-19 pandemic to improve access to care.[43]

Participatory approaches to research can have substantial cost benefits. Not the least of these benefits is the additional effectiveness of interventions when the knowledge, insights, values, and priorities of disproportionately impacted communities are understood and built into intervention efforts. Although this aspect is rarely assessed in published literature, a 2020 study described the hundreds of billions of dollars wasted in medical research, with a key contributor being limited relevance to the communities served.[44] Population health surveys are expensive to conduct, and cost-saving strategies often limit the inclusion of populations that are considered small, such as American Indian and Alaska Native and multiracial populations. Many studies incorporate census data, which are known to have significant flaws with respect to counting certain structurally marginalized populations, to develop sampling plans.[10,45,46] The systemic nature of racism requires us to acknowledge such limitations and consider alternative strategies to adjust for these deficiencies in the near term. Integrating participatory processes within these heavily funded studies can improve the focus of research to result in clinically and community-meaningful activities while also reducing waste.[44,47]

Operationalize data equity in public health

The COVID-19 pandemic demonstrated the limits of the Health Insurance Portability and Accountability Act when emergency exceptions waiving the Privacy Rule resulted in unprecedented disclosures of protected health information. The pandemic also brought to light deficiencies in an antiquated data infrastructure, resulting in large investments in modernization efforts and cross-sectoral data-sharing partnerships. Data equity refers to examination and improvement of the ways in which data are collected, analyzed, interpreted, and distributed in the context of health equity; data equity is inherently participatory.[48] Failing to honor data equity in public health practice is counterproductive to meaningful social change and can mask existing or emerging inequities. The Urban Indian Health Institute identifies the catastrophic impact of systemic "data genocide and data terrorism that is evident by being eliminated in the data and what scarce data is available being used to harm tribal nations and their citizens."[45] Similarly, inequitable data practices result in inaccurate interpretation of available information, leading to harmful practices, inadequate solutions, and worsening health inequities.[49,50]

As health inequities are often connected to historical trauma and prolonged oppression, data equity, including indigenous data governance and data sovereignty, is a critical concept for the public health community to adopt.[51,52] The intersectionality framework developed by American civil rights advocate and contributing scholar of critical race theory Kimberlé Crenshaw is a theoretical framework for understanding how multiple social identities intersect at the micro level of individual experience to reflect interlocking systems of privilege and oppression at the macro social-structural level.[26] Intersectionality is critical to operationalize in any data plan because people experiencing the greatest risk for inequities often have multiple social identities that place them at a risk for oppression. Racial justice is a vision and transformation of society to eliminate racial hierarchies and advance collective liberation.[53] A racial justice framework is foundational in all data practices because it is impossible to advance health equity and social change without it. Successfully implementing these or similar frameworks for data equity requires a participatory approach inclusive of structurally marginalized communities: Communities determine when the goals have been achieved.

Formalize power sharing and collective control

Power sharing and collective control have positive impacts on health.[54,55] Public health programs that focus on "empowerment" through unidirectional knowledge sharing are limited by their reliance on a deficit-focused understanding of health inequities that overemphasizes individual responsibility and fails to acknowledge or address systemic and structural barriers that result in disempowerment and ongoing health inequities.[56,57] A deficit-focused approach neglects the existence and intersection of resources that are already present in the community.[58] This approach is paternalistic and does not reflect a truly participatory approach to engagement.[55]

Public health institutions can work effectively with other sectors and communities as partners for advancing health and well-being.[33] Public health can recruit people with lived experiences of being marginalized into leadership positions, including executive-level and other roles that involve decision making and oversight of activities such as boards of directors.[42] Public health practitioners can also seek opportunities to partner with and support social movements for equity as foundational to promotion of health equity.[59] Such efforts are cost efficient in supporting and sustaining self-determined objectives and priorities of structurally marginalized communities.[59]

Public health research activities involving human participants are normally overseen by institutional review boards (IRBs) with responsibility for ensuring ethical and regulatory compliance. In many public health departments, IRBs also review proposed interventions and evaluation activities. IRBs are an essential part of the public health ecosystem, yet they often have requirements inconsistent with CBPR/CBPP and lack the ability to identify and assess community-specific concerns around research and data, monitoring and evaluation activities, or interventions, unintentionally placing communities at risk.[60,61] American Indian and Alaska Native communities responded to the inadequacy of many IRBs by establishing tribal institutional review boards.[62] This approach can be adapted to any community context by establishing community research review boards (CRRBs), an approach that includes training community members to conduct formal review processes associated with research, monitoring and evaluation activities, and public health interventions.[63,64] Similar to IRBs, CRRBs establish guidelines for activities within their community and have decision-making power on how activities proceed. CRRBs are made up of individuals with lived experience who represent the community to be studied, including community priorities and concerns relating to research. The successful implementation of CRRBs demonstrates feasibility, ethical alignment of research activities, and promotion of community benefits; such boards are an important step toward addressing systemic inequities and long-standing ethical dilemmas in research.[52,63]

Action Steps to Implement Evidence-Based Strategies

	Evidence-Based Strategy		Action Steps
1	Recognize that lived experience is expertise.	1a	Integrate community expertise in the public health process.
		1b	Compensate community experts: Integrate within budgets, prioritize lived experience consultancies, and identify opportunities to integrate lived expertise into systems.
		1c	Integrate a variety of participatory methods to capture unique aspects of lived expertise.
		1d	Expand training, credentialing, and career ladders for the lived expertise workforce.
2	Incorporate place-based approaches and environmental justice.	2a	Prioritize community-defined geographies in place-based public health practice.
		2b	Ensure accessibility of place-based activities.
		2c	Incorporate environmental justice into the public health process.

3	Develop action-focused community-feedback loops.	3a	Identify, acknowledge, and address power dynamics within a community and historical oppression/injustice.
		3b	Co-develop a collaborative decision-making and discussion plan.
		3c	Ensure inclusion of intersectional identities, with specific attention to accessibility.
		3d	Use structured assessments that include feedback loops, such as health equity/racial equity impact assessments.
4	Address knowledge gaps through CBPR approaches.	4a	Cultivate public and private support for CBPR that includes planning grants, training, and resources for documentation and evaluation.
		4b	Establish CBPR as the gold standard for research that advances health equity.
		4c	Integrate community expertise via multiple modalities throughout the research process; ensure that research aims meet community priorities.

		4d	Be reflexive about the identities of the research team and account for power dynamics in leadership planning and research design.
		4e	Document a collaborative plan for achievement of consensus and conflict resolution.
		4f	Include the community in data collection and analysis, interpretation of results, and dissemination of findings.
5	Operationalize data equity in public health.	5a	Build capacity around intersectionality and racial justice; integrate within data management and analysis plans.
		5b	Critically review existing data systems to identify knowledge gaps and populations routinely underrepresented/excluded.
		5c	Develop partnerships with identified communities to co-develop novel data streams.
		5d	Ensure that tools, methods, and approaches are community responsive.

		5e	Ensure inclusion of communities in leadership and decision making when interpreting data to mitigate biases, identify potential knowledge gaps, and center community strengths.
6	Formalize power sharing and collective control	6a	Ensure that policymakers engage community–public health partnerships in the process of policy-making and evaluation.
		6b	Formalize power sharing and shared leadership between institutional public health staff and community experts.
		6c	Facilitate the development of CRRBs and incorporate them into IRB workflows.

Opposing Arguments

Opposing arguments against CBPP in public health exist and are likely to evolve. They include those outlined below.

Lack of perceived interest in engagement from communities

Communities that continue to experience health inequities have both historical and present-day lived experiences that result in mistrust of public health systems.[65] It is important to consider that although there is no one “right” way to engage the communities we serve, there is potential for missteps: Community engagement has historically been deployed to tokenize or exploit communities. Failure to correct missteps can lead to devaluation of community input, further disenfranchisement, and spread of misinformation. Preventing potential missteps requires addressing the varied opinions that challenge the integration of CBPP approaches; acknowledging the history and current realities of underresourced communities, political tensions, and socioeconomic inequities that hamper engagement; and being trustworthy, holding central the tenet that authentic community engagement is vital for public health.[19,66,67] In addition, funders, such as the National Institutes of Health, are now requiring or strongly encouraging authentic community engagement.[68]

Definition of "community"

Although evidence is clear that there is immense value in community-level strategies and partnerships, debate on the definition of "community" can delay, impede, or even restrict engagement efforts.[19,32,33] While institutions regularly define community based on historic, administrative, or operational boundaries, communities often define themselves according to solidarity or common perspectives that can be difficult to quantify, locate, and even describe.[11,12,25] Public health practitioners must work in partnership with communities to consider community definitions that may challenge historic institutionally led definitions, which will often require negotiation with and acceptance of ambiguity by institutional leaders.[32,33] Use of fluid and community-driven definitions and recognition that communities may be geographic, identity based, or some combination are essential to effect partnerships.[14]

Lack of an evidence base

Leaders and community members may reject interventions that have not yet been proven by randomized controlled trials (RCTs), despite the known limitations of RCTs and the costs associated with certifying a practice as "evidence based."[69,70] Limitations in the evidence base for this type of work are plentiful, particularly because of the absence of representation of communities experiencing health inequities.[71] Too often studies focus on demonstrating the feasibility or acceptability of evidence derived from RCTs while ignoring the critical need for evaluation of success, barriers, and consequences to communities. In addition, such approaches may ignore the reality that evidence-based programs are organically adapted to be more suitable to the service population, resulting in poor fidelity to the model. As with defining community, negotiation with institutional leadership may be required to implement CBPP, especially when working to implement community-led and community-derived programs that may not yet have a robust evidence base.[68]

Insufficient resources

Public health practitioners work within the confines of modest and dwindling resource environments.[72,73] CBPP is thought to be time and resource intensive, and health departments and community-based organizations may not have staff to support such projects.[72] At a time when public health funding is under threat, many health departments, elected officials, and leaders of community-based organizations may be hesitant to invest resources in work not seen as mission critical or whose gains may not be achieved within a fiscal period or political term.[73,74] While it may be widely understood that there is demonstrable cost benefit in direct investment in public health, health equity strategies, and communities, cities and states facing fiscal constraints will inevitably direct resources toward low-resource solutions with shorter-term gains.[73,74] Increased engagement in CBPP may, over time, lead to innovations that reduce resource intensity.[25,74] However, institutional leaders must be careful to avoid quick-win solutions that lack long-term sustainability and results; the long-term costs of growing health inequities, ineffective interventions, and increasing mistrust outweigh the relatively small upfront investment often required by participatory approaches.[73–75] In fact, with the increasing adoption of online and virtual participatory strategies, resource limitations are becoming less of a concern.

Although truly participatory community engagement requires resources, time, effort, and forethought on the part of all parties involved, it is never too late to initiate such efforts.[16] Public health is ultimately about people, not necessarily credentialed scientists, politicians, or academic institutions. We cannot afford to leave people and their communities out of the equation.[25]

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