RESEARCH REPORT

Leveraging Community Expertise to Advance Health Equity

Principles and Strategies for Effective Community Engagement

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Contents

Acknowledgments

Leveraging Community Expertise to Advance Health Equity

Given the COVID-19 pandemic's disproportionate effects on people of color and increased attention to racial justice in the US,[1] initiatives to increase health equity are sprouting up across the country (Ndugga, Artiga, and Pham 2021).[2] These efforts range from addressing immediate health and social needs among communities most affected by the pandemic's impacts[3] to broader and longer-range policy changes designed to eliminate systemic barriers to good health.[4] This brief examines the role of community engagement in informing and advancing efforts to eradicate health inequities. Here, we define "community engagement" as collaborating and sharing power with communities to identify concerns and develop and implement solutions.

This brief draws on interviews with representatives from national organizations, health equity experts, and stakeholders in four states, including representatives from state agencies, community-based organizations (CBOs),[5] consumer advocacy groups, and foundations. Through these interviews, we investigated ways community engagement is being used to advance health equity and factors that promote or hinder community engagement. Many study participants expressed that community members are experts in their lives and communities who need resources and support to facilitate equitable community health and well-being. Though community engagement can take many forms, authentic and meaningful engagement in which community members are not just present but actively take part in decisionmaking requires extensive relationship and trust building that involves a significant investment of time and resources. However, interviewees acknowledged that a lack of institutional commitment, limited funding, and bureaucratic barriers impede efforts to effectively engage communities.

Our study participants shared numerous strategies to support effectively, authentically, and meaningfully engaging community members in health equity work, organized around four guiding principles:

- Community engagement relies on establishing trust.
    - » Be humble, listen, and act on feedback.
    - » Be transparent.
    - » Partner with trusted community leaders and CBOs.

- Community engagement requires sufficient and flexible funding and cross-sector support.

  » Secure flexible and sustainable financial resources.

  » Adequately compensate staff and community members.

  » Collaborate across public health, health care, and social service sectors.

- Community engagement should be continuous and sustained.

  » Allocate considerable time and patience.

  » Provide infrastructure, technical assistance, and support.

  » Follow through and "close the loop."

- Community engagement should pay explicit attention to eliminating structural racism.

  » Hire from the community.

  » Address participation barriers.

  » Address racism inside and outside governments and organizations.

Our study participants believed health equity initiatives that include authentic and sustainable community engagement are needed to more fully understand complex drivers of inequities and to develop solutions that lead to inclusive and sustainable progress toward health equity. To meaningfully incorporate community voices, governments, health care and social service organizations, philanthropies, and others conducting health equity work can partner with community-centered, culturally and linguistically effective, and trusted organizations and support them with sufficient resources. Over time, this could lead to greater oversight and accountability for advancing health equity and, ultimately, more progress in eliminating systemic barriers to all community members achieving their maximum health and well-being.

We've got to be prepared to invite the community to participate in decisionmaking. It's not, 'We're going to take your input on advisement,' it's, 'We're going to decide together what to prioritize and how that work's going to happen.'
—Study participant

Background

In the US, the pandemic has resulted in large racial and ethnic disparities and highlighted systemic inequities in both health and economic well-being. For example, Black, Latinx, and American Indian and Alaska Native populations have faced disproportionately high risks of getting seriously ill from COVID-19 and have suffered higher rates of job loss and financial instability than white people during the pandemic.[6] State and local governments have responded variously to address these disparities and promote greater health equity during the pandemic and in the long term, including convening health equity task forces, improving racial and ethnic data collection and analysis efforts to monitor disparities, and collaborating with communities of color to improve access to testing, vaccines, and other resources (Ndugga, Artiga, and Pham 2021).[7]

Federal, state, and local government agencies are responsible for including the public in program and policy development via public notices, public hearings, working groups, consumer surveys, and other stakeholder engagement activities that increase government transparency and accountability.[8] For example, federal law requires that Medicaid beneficiaries are represented on advisory and governance bodies to provide input to Medicaid agencies and community health centers on policy and programmatic decisions (HRSA 2018).[9] Federal regulations and statutes dictate that state government agencies consult with tribal governments around certain public policies that may affect tribes.[10] Despite a long-standing history of stakeholder outreach and engagement in public policy, little is known about the role and impact of consumer advocates and community members in shaping public policy decisions and program administration.

Community engagement has long been promoted as a tool for improving public health. More than 20 years ago, the Centers for Disease Control and Prevention defined community engagement as "the process of working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the wellbeing of those people…[to] serve as catalysts for changing policies, programs, and practices" (CDC 1997). Community engagement differs from stakeholder outreach. The latter is informing the public or seeking their input, which Petiwala and colleagues (2021) describe as including "passive community voices." Community engagement, however, is a collaborative relationship with community members to identify and address community concerns, or including "active community voices" (table 1; Petiwala et al. 2021). At its fullest, community engagement centers community members and provides them with resources and support to assess and prioritize community needs, identify solutions, implement interventions, and evaluate whether programs and policies are addressing community needs. We therefore reserve the term "community engagement" for efforts that give communities power.

TABLE 1
Stakeholder Outreach versus Community Engagement

Stakeholder outreach	Community engagement
▪ Convening focus groups, surveys, and town halls to gauge community concerns ▪ Developing initiatives to solve problems identified by the community ▪ Supporting community members' involvement (e.g., by providing transportation, child care and food at community meetings) ▪ Developing short-term solutions to address health disparities (e.g., initiatives to reduce the prevalence of diseases among certain groups in the community)	▪ Collaborating and sharing power with communities to identify their priority concerns and solutions ▪ Investing in community-led initiatives to develop and implement solutions (e.g., governments and organizations can provide funding, training, and other resources and facilitate connections) ▪ Sustained, ongoing investment that allows for shared power (e.g., by hiring and adequately compensating community members to serve as community health workers, researchers, or governance members) ▪ Engaging in long-term capacity building, leadership development, and trust building to address underlying social determinants of health and reduce long-standing inequities and evaluating the effectiveness of such efforts

Sources: Shavon Arline-Bradley (founding principal, R.E.A.C.H. Beyond Solutions), presentation given December 2019, and key stakeholder interviews.

Effectively engaging communities in policy and systems change is especially important given the role the public sector has played in perpetuating health inequities by reinforcing racist policies and practices and enabling inequitable resource allocation (Brennan Ramirez, Baker, and Metzler 2008; Gee and Ford 2011; Kijakazi et al. 2019; National Collaborative for Health Equity and CommonHealth Action 2015; Solomon, Maxwell, and Castro 2019; Williams, Lawrence, and Davis 2019). For this study, we sought to understand how community engagement plays out on the ground and what factors promote or hinder authentic, meaningful, and sustainable community engagement as states grapple with how to improve health equity during and beyond the pandemic. To do so, we interviewed stakeholders involved in or affected by public and private community engagement initiatives in Colorado, Mississippi, Oregon, and Rhode Island. The following sections provide an overview of our research methods, followed by findings on how interviewees define community engagement, the barriers they observe to successful community engagement, and principles and strategies to support effective community engagement in health equity work. We conclude with a discussion of the implications of our findings for public and private efforts to advance health equity.

Methods

We first conducted eight interviews with health equity research and policy experts and representatives of national associations focused on public health, health care, and health equity to inform the direction of the project and our selection criteria for case study states. We asked

interviewees about their perspectives on the most important components of state health equity efforts, the ways such efforts incorporate community voices, the policy levers states use to advance health equity, and the main challenges such efforts face. We also conducted an environmental scan of publicly available information on states' health equity work to date. We then selected Colorado, Mississippi, Oregon, and Rhode Island for their geographic and demographic diversity and because the government, philanthropies, and/or CBOs in the states were focusing on developing health equity initiatives through community engagement. Appendix A describes selected community engagement efforts and mechanisms in each state.

During March and April 2021, we conducted 19 interviews with 25 stakeholders across the four states. We identified interviewees familiar with the structure of the state's health equity work and how the state gathers community input, as well as others informed about specific public- or private-led community engagement efforts. Specifically, we inquired about interviewees' most important concerns related to health equity in their areas, how they defined health equity, how they incorporate community input into designing and implementing initiatives, and their successes, challenges, and lessons learned. Ultimately, we spoke with representatives of CBOs, community organizers and consumer advocates, philanthropic funders, and staff from state public health and health equity agencies. These representatives focused on improving health and well-being in specific communities, such as immigrants, refugees, and migrant workers; people with disabilities; people who identify as LGBTQIA+; both rural and urban communities; uninsured and underinsured people; people experiencing homelessness; people with unhealthy substance use; and American Indian and Alaska Native, Black, and Latinx populations.

The research team recorded, transcribed, and analyzed the interviews for common themes and key insights. Because we interviewed a small number of stakeholders, we may not have captured some important experiences and perspectives. Further, our findings cannot be generalized across all subgroups or states.

The community advisory board for the Urban Institute Health Policy Center's Transforming Health and Health Care Systems project informed the direction of this project. The Urban Institute's Institutional Review Board approved our study methods.

Findings

Though our interviewees varied in how they define and implement community engagement and identified different barriers to effective community engagement, they offered several considerations for states and organizations to build trust with disenfranchised communities and to more effectively engage them in advancing health equity.

How Are Health Equity and Community Defined?

According to the Robert Wood Johnson Foundation, health equity "means that everyone has a fair and just opportunity to be as healthy as possible," which requires, "removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care" (Braverman et al. 2017). But definitions of health equity can and do vary by community needs. Many of our key interviewees expressed the importance of states, CBOs, and community members developing a shared definition of health equity. In many cases, study participants reported using a broad definition that includes not only sufficient prospects for all community members to achieve good health but equity in social determinants of health, too, including stable housing, adequate nutrition, and financial stability. Some expressed the fundamental importance of acknowledging and combatting systemic racism as a driver of health inequities for people of color, and others included in their definitions additional characteristics that may put people at a systemic disadvantage, such as immigration status, limited English proficiency, sexual orientation, gender identity, geographic location, and disability status.

Several interviewees acknowledged that operationalizing health equity is an ongoing process that requires shifting culture and educating policymakers and the public. As one interviewee explained, "There's a misconception...that if we're addressing health disparities, we're addressing health equity, and they're not one and the same." Another interviewee stressed the importance of recognizing past and present injustices as an important component of community engagement, stating that health equity efforts should include "working towards the equitable distribution or redistribution of resources and power and recognizing, reconciling, and rectifying historical and contemporary injustice." Yet another study participant added that one benefit of the pandemic is that it has forced health equity to be a part of broader conversations.

Interviewees also offered various definitions for "community." Several study participants defined communities as groups of people living in a specific geographic area. One interviewee defined community as people of similar characteristics, such as "race and ethnicity, language, and self-

identification" but recognized a community may not be homogenous or geographically defined and can be fluid as demographics change. One interviewee from a rural community considered the most disadvantaged community members in their definition; they believed community representation in health equity initiatives should include more people from marginalized groups, not just those who mirror the community's racial and ethnic distribution.

A few interviewees stressed the need to recognize intersectionality, that people may face multiple marginalized statuses (e.g., related to race and ethnicity, immigration status, or disability). One interviewee noted, "The barriers do seem to get bigger the more oppressed identities one holds." Another interviewee commented that understanding where people are coming from and the complex challenges they face is important to trust building, saying, "We're not asking you to show up as an immigrant, we're asking you to show up as a whole person." Yet other interviewees were hesitant to define a community. One study participant said, "The worst thing that we [as officials] can do is to put definitions [on] people." This participant said the same of defining "lived experience," too. Instead, these interviewees expressed that community members should decide how they want to be defined, who among them should represent their voices, and who should lead health equity work.

Lastly, several study participants flagged the need for special consideration for including American Indian and Alaska Native populations in health equity efforts and community engagement. One of our interviewees noted that tribes are "not a community or a community of color" but instead are sovereign nations. Therefore, states' interactions with tribal governments are on the government-to-government level, and, as mentioned above, states must have a policy in place to properly consult with tribal governments on matters that may affect the tribes.

Why Is Community Engagement Important?

Inequities in poverty, hunger, and financial opportunities among people of color and other marginalized populations persist despite decades of public and private investments, and the pandemic has exacerbated these imbalances.[11] Because these underlying inequities contribute to poor health, some interviewees thought prior efforts to improve population health may not have adequately considered the root causes of health inequities. As such, many thought collaborating with and shifting more power to historically marginalized communities are critical to better understanding and removing barriers to good health and deploying resources where they are most needed.

Similarly, several interviewees stated community members are experts in their communities and can create and implement solutions to their communities' problems. One interviewee described that it

was "dumb to think that [she] could sit in this marble building...and figure out what's going to work in...[a] rural community." The same interviewee added, "They knew what their problems were, they were easy for them to articulate, and they had proposed solutions." Another interviewee explained how community-informed solutions to health equity challenges can be effective:

> "What makes the community engagement piece so critical is that anytime we're trying to serve a population of people, and particularly as a government agency, if we're not taking the time that we need to develop relationships and to develop trust, then we're not going to be hearing from them about what the factors are that are impacting their lives. And if we don't fully understand the context of that, then our work is just a big guessing game."

According to our study participants, taking a local focus (rather than statewide) is another key way community engagement can make health equity efforts more effective. Some interviewees described approaches to addressing health disparities that proposed common solutions across a state rather than considering local or regional areas' different concerns. This meant some areas' concerns were not prioritized in planning or resource allocation, and thus efforts fell short of meeting communities' specific needs. Many interviewees agreed that locally focused initiatives are key to addressing health equity, because communities have different demographic compositions, challenges, and strengths. One interviewee shared the following:

> "When you're working at...a neighborhood or city level, you're...really able to leverage the expertise and the resources and the leadership amongst...organizations, amongst residents, amongst churches, and city government and...marshal all of that. Obviously, people who come from the community have a much more nuanced understanding of what the issues are, what the needs are, but also what some solutions are going to be and what kind of resources can be brought to bear."

Having established community engagement methods that reflect local concerns can allow for more successful responses to pressing needs. Some interviewees mentioned that having existing means of engaging communities and established relationships allowed for faster responses to new pandemic-related priorities, such as distributing public health information, vaccines, and other resources to hard-hit communities. In another community, community health workers saw a need for financial support for undocumented workers during the pandemic and worked with state officials, advocacy groups, and philanthropic donors to develop a solution. One interviewee reflected, "None of that could have been half possible without the years of advocacy and the relationships built and Latinx members of our state legislature, who also got there because of grassroots efforts and community building on the local level."

What Are Some Barriers to Effective Community Engagement?

Though many stakeholders identified community engagement as important, they acknowledged that it is hard to implement effectively and identified several challenges to authentic, productive community engagement.

From our conversations with national and state interviewees, we learned of underinvestment in public health and health equity and failure to support community-driven solutions in many locations across the nation. Though we found through our scan of publicly available information that nearly every state has an office dedicated to health disparities or health equity within its public health department (e.g., an office of minority health or office of health equity), the resources and respect these offices hold can vary notably across states; some agencies have to fight to work health equity into policy discussions and decisionmaking (Himmelstein and Woolhandler 2016; Zelman and Stevens 2020).[12] These agencies may not have the staff and resources to extensively engage the community or expand their focus from chronic disease prevention to addressing social determinants of health or systemic racism (and this may not be politically palatable in some communities). However, some interviewees noted the pandemic has elevated the importance of public health and health equity; some state health equity programs are receiving attention from state leadership for the first time, and states with smaller health equity initiatives may now be interested in broadening those efforts.

Similarly, representatives from several small CBOs in our study were frustrated about not having enough resources or capacity to be in all the important conversations about health equity, being overlooked in outreach by state and local governments, or being locked out of funding opportunities. One interviewee noted that though their organization maintains regular contact with the public health department, other state agencies may not know to reach out to the organization on matters relevant to the community it serves. Several interviewees described frequently having to force their way into relevant conversations. As one CBO representative said, "If people don't invite me to places, I invite myself. I have to make sure that I can be there and provide my two cents or at least have people listen [to] what I know and invite others to come along with me."

Interviewees noted that many CBOs are beginning to receive greater attention from government agencies, foundations, and others because of their deep expertise in their communities, culturally and linguistically effective practices, and long-earned trust of community members. However, our study participants also pointed out that many small CBOs lack the resources, skills, and capacity to compete for funding with larger organizations. This is in part because of burdensome bureaucratic procedures, such as complex and resource-heavy applications requirements and grant reporting guidelines.

Funding opportunities may also lack flexibility to support community-driven work, such as by imposing strict education or licensing requirements for community health workers and peer specialists or requiring that a certain share of funding be allocated to culturally specific organizations, which can be difficult in some areas. As one study participant noted, governments and philanthropy may need to carefully consider how funding mechanisms can better support community-led health equity efforts.

Informants flagged other barriers and challenges to community engagement, most chiefly the mistrust and disappointment members of disadvantaged and marginalized communities may feel toward governments and other public and private institutions. These include health care, academia, and philanthropic entities. One interviewee explained, "I will say the other thing is recognizing that it takes time and it takes resources to build authentic relationships and trust within community, especially communities that are so tired of being surveyed, of being interviewed."

A few interviewees also warned about the dangers of tokenism in community engagement. One interviewee mentioned that sometimes communities are consulted when a decision has already been made, "to rubberstamp it." Another interviewee recognized that because of diversity, equity, and inclusion requirements, she may be invited to meetings just so the conveners can meet representation requirements. Yet another stressed that community engagement can turn into tokenism when it becomes institutionalized in governments and organizations:

> "We want to make sure that employees who are going to use this [community engagement guidance] document are educated: Why is this important? What does equity mean? And how to intentionally do it and not just say, 'Okay, we got to have another meeting. We got to give these people 20 bucks for their time.'"

Another interviewee suggested that large bureaucratic institutions with countless rules and regulations are also slow to change, but organizations need to be nimble and react quickly when community demographics and priorities change. Other barriers for governments and organizations include frequent staff turnover (which can undermine trust and relationships), lack of executive leadership focusing on community needs, lack of institutional diversity (at the leadership level in particular), and systemic racism and implicit bias, which can be pervasive and deeply embedded across public and private institutions.[13] In addition, a lack of attention to removing participation barriers related to transportation, language, or child care may prevent community members from participating in health equity efforts. For example, one interviewee acknowledged their organization excludes many community members from health equity work because it lacks capacity in the numerous languages community members speak.

What Are Effective Principles and Strategies to Support Authentic Community Engagement?

Interviewees offered several strategies that governments, health care and social service organizations, philanthropies, cross-sector coalitions, and others could consider to more effectively and authentically engage communities to improve health equity. Below, their suggestions are organized by four core principles of community engagement:

1. Community engagement relies on establishing trust.

2. Community engagement requires sufficient and flexible financial resources and cross-sector support.

3. Community engagement should be continuous and sustained.

4. Community engagement should pay explicit attention to eliminating structural racism.

PRINCIPLE 1: COMMUNITY ENGAGEMENT RELIES ON ESTABLISHING TRUST

Take a humble approach to relationship building that includes actively listening and acting on feedback. Almost across the board, interviewees stressed that meaningful, authentic, and sustainable community engagement rests on trusting relationships. On the part of state and local governments and organizations, this means being willing to listen to and incorporate feedback from CBOs and community members. Multiple interviewees emphasized that true community engagement is not about approaching the community with a health equity agenda but rather letting the community define problems and collaborating with them in formulating solutions. One interviewee called this approach "the art of public health." That interviewee emphasized that officials or funders should not present themselves as experts but should instead build trust within a community and help community members understand they are there for the community's benefit and can guide community members and provide support and resources to address community challenges.

Another interviewee advised to humbly ask questions that do not just focus on challenges (a deficit-based approach) to learn about a community; instead, they suggested asking about the community's strengths and sources of pride. To earn the trust of communities, interviewees argued that governments and organizations need to listen to community input and act on it, which may require doing things differently. One interviewee described a project in which grantees wanted to present to the community about how they had used the grant funds instead of writing traditional final reports. The interviewee acknowledged that this required additional work for the staff (e.g., providing

support and resources for grantees to prepare their presentations), but the end result was "a beautiful experience for the community to see" and even allowed them to raise more money for the project.

Be transparent. In the same vein, being transparent about reasons for collecting information and how it is going to be used, sharing draft plans, being forthcoming about constraints, and explaining why certain suggestions cannot be implemented can also help build trust with a community. As one interviewee explained, a lack of transparency can fuel mistrust:

> "I think a lot of the time, especially within state government and city governments, we see a lot of decisions being made that are in misalignment with what community has said we need. And then we never hear why. And then there's a lot of anger and distrust toward those entities, when in reality, oftentimes it's a federal rule or a federal law that disallows them to take the feedback of the community and move forward with it. And when that happens, if they tell us, it's not going to break that trust, right? It's going to make sure that we want to continue working with them in the future. And more importantly, if we know what the barriers are on the state and local level to get what we need as a community, we'll fight with the state and local level against the feds to make the changes that are necessary."

Partner with trusted community leaders and CBOs. If they lack established relationships and trust with community members, governments and organizations can consider partnering with appropriate CBOs and community leaders to broker trust. As one of our interviewees explained, hiring staff from the community, conducting community needs assessments and surveys, and convening a community advisory board are ways their organization ensures programs and services and the manner in which they are delivered meet the community's needs and preferences. Staff at CBOs are often experts in community matters, have earned the trust of community members over a long period, and can advocate and organize community members for policy and systems changes. Further, several interviewees mentioned that CBOs often are culturally and linguistically effective and have more flexibilities to adapt and respond to changing community priorities than many governments or other private institutions. CBOs can also be well positioned to be intermediaries between state governments, academia, philanthropies, and communities.

PRINCIPLE 2: COMMUNITY ENGAGEMENT REQUIRES SUFFICIENT AND FLEXIBLE FINANCIAL RESOURCES AND CROSS-SECTOR SUPPORT

Secure flexible and sustainable funding. Several interviewees identified providing financial resources to implement community-designed solutions to health inequities as the most critical evidence that community input is valued. As one of our interviewees suggested, "putting money where your mouth is" is an effective way to demonstrate commitment to addressing structural racism and health inequities. One interviewee suggested a state budget is the most important policy document that can

drive change. Yet another said releasing statements and proclamations about racism and health equity comes across as insincere if not supported by actionable steps and the allocation of resources.

Both state officials and representatives of CBOs reported relying on funding sources such as federal grants, state budget allocations, and philanthropic funding for health equity and community engagement work. However, they faced challenges securing adequate and sustainable funding. Representatives of CBOs reported having to constantly fundraise, or, as one interviewee put it, "fight for dollars," to implement initiatives. That interviewee also indicated that lack of sustainability meant their organization could not rely on predictable resources. Because communities are not stagnant, resources need to be flexible and enable CBOs and service providers to "give the community what they want when they want it," as one informant put it. Robust, sustained, and flexible funding for CBOs and other organizations serving community needs, along with streamlined grantmaking and cost reimbursement systems, could better support community-led health equity efforts, including by allowing smaller organizations to more easily participate. For example, a couple of foundations in our study and others around the country are implementing participatory grantmaking strategies,[14] which incorporate community engagement in funding decisions.

Adequately compensate staff and community members. Interviewees noted allocating specific resources in budgets for community engagement as a key strategy both for hiring and properly compensating state agency and organizational staff and community members. This funding can prevent turnover and burnout among agency and organizational staff and values the time and energy of community members who provide input, participate in projects, and organize the community to support a cause. One interviewee emphasized that paying someone for their expertise and participation is "honoring and acknowledging that this person's information is valuable, and it's not something that can be given to you for free." Another interviewee commented that state governments often hire expensive consulting firms to develop policies but expect CBOs to work for free because it is in their mission to serve. In turn, this can suggest CBOs are not valued and their input can be easily disregarded because it costs nothing. One interviewee said the following:

> "We often ask people [community members] who have this expertise to come in and help us, to let us pick their brain. And essentially what we're doing is we're taking advantage of their time and capacity and expertise, and we're not properly resourcing them as we would any other consultant, or even...thinking about our own staff as we're hiring...folks who have that skill set that we desperately really, really need."

Collaborate across public health, health care, and social service sectors. Community engagement may be more effective if it is multidimensional, so funding should also be broad based, spanning multiple sectors. Recognizing that good health is not just access to health care but secure housing, fair wages,

and other social determinants of health, some CBO representatives noted that though their organization may have a good relationship with the state or local public health agency, it may not have connections to other agencies that oversee sectors closely connected to its clients' needs. In contrast, a few CBO representatives talked extensively about working in partnership with others in the community to collectively address the range of their communities' needs. One interviewee commented about how their organization always thinks of ways to include other CBOs in the community in grant funding and to find resources to build local partner organizations' capacities through formal subcontract agreements. Another interviewee remarked that robust community partnerships across different stakeholders and entities also support greater community buy-in for health equity initiatives. Informants said similar coordination across state and local government agencies was also essential, particularly because, as mentioned earlier, CBOs may not have time and resources to represent themselves in every important meeting or conversation.

PRINCIPLE 3: COMMUNITY ENGAGEMENT SHOULD BE CONTINUOUS AND SUSTAINED

Allocate considerable time and patience. Engaging communities is a long-term process that includes both addressing immediate challenges and thinking strategically about longer-term leadership development and capacity building so community members can effectively advocate for their needs and lead health equity initiatives. Forming authentic relationships with communities therefore requires considerable time and patience. Several interviewees described establishing relationships as going out into the community and meeting people where they are (e.g., local organizations, restaurants, churches, and community events) and getting to know them personally. This can be difficult to manage when government and organizational leaders have other responsibilities, like reporting to their boards and fundraising. It also suggests organizations should consider that committed engagement requires time beyond a traditional nine-to-five schedule. One interviewee shared the following:

> "It's very exhausting. It's very time consuming, and it's hard. It's hard work, and it is much easier to create a survey on SurveyMonkey or whatever and email it to a bunch of people and get those responses back and create a pretty chart that you can show your investors, your stakeholders, or whatever. That's super easy. But to do authentic community work with community takes a lot of time and money and patience."

Provide infrastructure, technical assistance, and support. Multiple interviewees emphasized that community engagement is about more than providing an avenue for the most disenfranchised communities to designate their priorities and propose solutions; it is also about developing leadership skills and building capacity for community members to effectively address their current and future challenges. To support community-led solutions, state agencies and organizations can serve as "backbone" agencies, "recognizing that residents are going to need a fair amount of support and

scaffolding in most cases to be able to fully participate at the table," as one study participant explained. As backbone agencies, governments and organizations can provide support via infrastructure, trainings, technical assistance, and establishing learning communities. Backbone agencies can also identify and convene multisector partners.

Several key interviewees pointed to longer-term leadership development, such as empowering young people to "find their voices," as one interviewee said, as an effective tool for sustained progress toward health equity. Several study participants talked about working with underrepresented groups, such as people of color, women, and people who identify as LGBTQIA+, to get them into elected offices, involved in politics, and on various boards where they can represent their communities' interests. Others spoke about helping staff at small, local CBOs, which are often underresourced, develop skills and competencies to fundraise, be more responsive to community needs, and more effectively advocate for change. As one of our interviewees described, capacity building is much more than enrolling employees in a leadership development course, and it is not "one size fits all."

Follow through and "close the loop." Another way governments and organizations can show how much they value community input is dedicating funding for evaluating health equity initiatives and disseminating results. Evaluations can show whether initiatives are working, and those conducting them can show follow-through to community members by sharing the results of their research projects or the end products of their engagement with the community. Evaluation can include developing and using benchmarks to measure how well efforts are incorporating community feedback (e.g., how often and how many community members attend meetings and provide feedback) or attempting to assess the effectiveness of health equity efforts. For example, one group reported measuring the share of non-English-speaking Medicaid patients who use translation services over time as a proxy for the initiative's success at improving health equity. Evaluation findings can inform where interventions need to be rethought or revised, and when evaluations show positive results, they can help achieve more community buy-in and sustained investment in interventions. But our study participants recognized that achieving health equity is a long-term goal. One interviewee acknowledged that progress takes time:

> "It's going to take quite a while to see if our efforts are reflected in the health outcomes of the communities that we are serving. We tend to look into these like really quick evaluations just to make us feel better, but at the end of the day, I don't expect to see anything until 5, 10, 15, 20 years from now. I mean true change, not the feel-good changes, which is the processes and things like that; I mean those are different things. But true health outcomes: It's going to take a while."

PRINCIPLE 4: COMMUNITY ENGAGEMENT SHOULD PAY EXPLICIT ATTENTION TO ELIMINATING STRUCTURAL RACISM

Hire from the community. Governments and organizations with diverse staff at all levels, including in leadership positions, can help improve understanding of health inequities and work to address them. Community engagement specialists and community health workers who have lived experiences or are from the communities they serve can more effectively engage community members, including hard-to-reach populations such as undocumented immigrants, people experiencing homelessness, or people with unhealthy substance use. But interviewees cautioned that organizations must be careful to avoid tokenism in their hiring decisions, that is, they should not just hire someone who looks like they are from the community; instead, organizations should hire, listen to, and provide resources to community members so they can effectively serve as intermediaries. Staff members responsible for community engagement ideally understand and are trusted by the community, are well-versed with government policy, and can effectively engage agency leaders, policymakers, and legislators. Thus, leadership development is a critical support.

In addition, multiple interviewees stressed that community health workers should not be hired using traditional recruitment strategies. Community health workers do not necessarily need to meet formal educational requirements or to have received health-related training, but as one interviewee noted, "They have to be respected and they have to have the desire to help their community." Organizations therefore often find their most successful community health workers already engrained in the community. Interviewees also supported providing cultural effectiveness training for staff working on health equity efforts.

Address participation barriers. Removing barriers that prohibit community members from participating in health equity work can lead to more inclusive community engagement. Study participants identified several basic steps to effectively engage community members in such initiatives, such as providing transportation, child care, refreshments, translation and interpretation services, and disability accommodations (e.g., materials for people with visual impairment) at convenings. Offering multiple options to engage at different times of the day, on different days of the week, and across various settings can also help facilitate community engagement. Additionally, technology access is critical; one interviewee described how their organization was able to extend community WiFi in a neighborhood with broadband limitations and relied heavily on text messages to connect with residents. These actions can break down systemic barriers to engagement that may disproportionately affect communities at highest risk of experiencing health inequities.

Several interviewees used the term "language justice" when talking about needing to make information and meetings accessible to people with limited English proficiency. One interviewee said language access should not be an afterthought, and instead all materials from schools and other public entities should be translated and available in all of a community's languages. Additionally, one state convened a Spanish language–only gathering and provided translation equipment for English speakers (rather than the opposite) to facilitate Spanish speakers' comfort and show it valued its Spanish-speaking partners.

Removing power dynamics and using accessible language are also important for making community members feel comfortable sharing their stories. Several interviewees acknowledged that having an elected official or representative from a state agency in the room could be intimidating (especially when wearing business attire), so community events may be more productive when staffed by community members. Using plain language and staying away from jargon during community meetings can also help facilitate community members' participation. Equally essential is making community involvement feel safe, particularly for those in groups who may feel unsure about engaging because of historic or ongoing threats to their safety.

Address racism inside and outside governments and organizations. Though hiring from within the community can help bring diverse perspectives and experiences into governments and organizations, study participants acknowledged that may be insufficient to overcome internal and external resistance to health equity. One interviewee raised an example of external resistance: once it became apparent that a health-related initiative in a rural county was addressing disparities, many people who had been interested in participating dropped out because they did not agree that the county had systemic inequities. Another interviewee described the situation as an urban-rural cultural and ideological divide in a predominately white state, saying pockets of the state where health equity is unpopular made it challenging to prioritize health equity statewide. Governments and organizations can employ strategies to eliminate racism from within, such as providing antiracist and implicit bias trainings, working with staff to improve workplace culture, and establishing diversity, equity, and inclusion initiatives.

Discussion

The COVID-19 pandemic has revealed and exacerbated long-standing racial and ethnic inequities in health and well-being, leading many state and local governments and private organizations to strengthen existing or create new health equity efforts. Our interviewees identified the importance of

integrating community voices into these efforts, not only to more effectively identify pressing problems and promising solutions but to share power, resources, and support with community members who can decide how to improve the health and well-being of their communities.

Many interviewees emphasized that CBOs play a key role as intermediaries between state and federal governments, philanthropies, and the communities where people experiencing inequities live. CBOs that are culturally and linguistically competent, trusted sources within their communities, and often serving the most marginalized and disenfranchised communities can be essential resources to meaningfully address the most important community concerns about health equity. However, CBOs may lack adequate resources to engage communities more widely. Thus, several interviewees suggested health equity efforts could be strengthened by allocating more resources to CBOs, so they can respond effectively to community needs. State agencies and philanthropic funders can serve as backbone agencies, convening and supporting CBOs in their work. Many study participants also emphasized that responding to diverse concerns and needs of various communities also requires a local or regional approach, as opposed to a statewide strategy.

Several interviewees emphasized the need for federal and state governments to adequately fund public health and health equity efforts and equitably distribute resources to communities disproportionately affected by health inequities. We heard repeatedly that money can express value, and allocating funding and equitably paying for community expertise are the most basic steps toward building trust with communities and demonstrating commitment. As Petiwala and colleagues (2021) explains, as communities are empowered and their input goes from "passive" to "active," the requirements placed on community members also increase, which can be difficult to sustain. It can also be especially disadvantageous for underresourced communities if efforts are insufficiently funded (Petiwala et al. 2021).

Interviewees also expressed the importance of reconsidering rules, regulations, and requirements that may prevent the organizations with the most expertise in community affairs from competing for funding opportunities. They also described how some organizations may choose not to compete for inflexible funding streams in which the money cannot be used to address the concerns or meet the preferences of the communities they serve. According to some interviewees, some grant rules have been relaxed and flexibilities on where resources can be directed have been permitted during the pandemic; to advance health equity beyond the pandemic, states and organizations may want to assess which pandemic flexibilities can be sustained.

Our study participants reported that efforts to engage communities had allowed them to build trust in the community and often made their health equity initiatives more responsive to community needs. Incorporating community voices can also have other benefits, such as adding to an effort's sense of urgency, providing data needed to inform decisionmaking, and illustrating an organization's sincerity. Over time, the latter can strengthen partnerships and lead to increased funding, which can then help ensure efforts are sustainable (Carney et al. 2014; Mt. Auburn Associates 2019; Petiwala et al. 2021). However, measuring whether community voices have been adequately represented, power has been shared, and trust has been gained may be difficult. Moreover, whether community engagement can meaningfully reduce or eliminate health inequities is largely unknown. This owes in part to a lack of evaluation efforts and inadequate existing efforts, though work is ongoing to develop measures that go beyond process metrics (Anderson et al. 2018; Davis 2015; Liburd et al. 2020; Penman-Aguilar et al. 2016).[15] Knowledge about the impacts of community engagement is also lacking because observing changes in health and other outcomes requires time.

In addition, many individual-, community-, and system-level factors influence health and well-being. Ultimately, achieving health equity will likely only be possible in concert with larger efforts to address systemic and structural racism, such as robust data collection that monitors inequities and holds governments and institutions accountable for equity (Hardeman, Medina, and Kozhimannil 2017; Johnson-Agbakwu et al. 2020). Similarly, efforts to advance health equity will also need to extend beyond state and local health agencies to include health care providers and insurers (including Medicaid programs), federal agencies, federal and state legislators, researchers, and others. This will require multidimensional collaborations extending to the health care, housing, educational, employment, immigration, and criminal justice systems (Johnson-Agbakwu et al. 2020; NPWF 2019).[16]

Recent focus on increasing community engagement across various sectors, such as directives from the Biden administration and efforts to involve communities in philanthropic decisionmaking,[17] indicate a new awareness of the need to authentically include community voices in addressing health inequities. Resources to effectively engage with communities are also becoming more widespread (appendix B). Governments and organizations with long-established health equity initiatives and those just beginning to tackle health inequities in the wake of the pandemic and renewed calls for racial justice can further their efforts through community engagement. But interviewees cautioned that new efforts will require establishing trusting relationships that are built over time. One stakeholder said their state's pandemic response was impactful only because of its ongoing health equity initiative funding structure that supports CBOs, which they described as "this ready-made infrastructure that [the state] could start pushing community response efforts through." Thus, amplifying opportunities

for community engagement could be essential for fighting not only the COVID-19 crisis but addressing future crises that affect community health and well-being.

Conclusion

Effective community engagement could make health equity efforts more successful. In turn, that success can increase political will and funding to fight inequities, which can make health equity efforts even more impactful. However, our findings could also inform efforts to engage community members in academic and clinical research, social and environmental justice work, or other areas. Community engagement can take various forms, and stakeholders we interviewed emphasized the importance of developing trust with communities, ensuring adequate funding, dedicating time and patience, and fighting structural racism more broadly to facilitate effective and meaningful community engagement and progress toward health equity. The urgency of the pandemic is not only a challenge but an opportunity to elevate community voices to better understand key drivers of inequities and develop solutions with community buy-in. More research and evaluation are needed, however, to fully understand the impacts of community-engaged policymaking and program development on the health and well-being of populations and improvements in health equity.

Appendix A. Examples from Case Studies

Interviewees highlighted various methods state agencies, funders, community organizers, and CBOs have taken to involve communities in the creation and implementation of health improvement plans and health equity initiatives. Health equity agencies in each study state have established formal channels for community representatives and CBOs to inform health equity initiatives and policies, such as working groups and advisory committees.[18] Frequently, state agencies and organizations reach out to communities to collect and exchange information and build partnerships with trusted community leaders and culturally effective organizations. More advanced initiatives may rely on networks of CBOs and community organizers to work with community members to identify local needs and strengths, develop programs, and provide resources and technical support to implement these programs. Table A.1 describes examples of strategies commonly used by the public and private sectors that could be leveraged for more effective relationship building; these have been effectively used in some of our study states and can serve as first steps toward more meaningful community engagement.

TABLE A.1

Examples of Mechanisms to Increase Community Engagement

Example	Definition
Community advisory councils	Community advisory councils provide guidance for organizations and agencies tasked with addressing social determinants of health. Their membership consists of the population served, "ensuring that the community voice is centered," as one interviewee said. But inclusion is not sufficient to engage community members; organizations must respond to boards' recommendations and show how plans and feedback are being implemented. One interviewee said that when an organization's board reports to their advisory council and says, "Remember that meeting we had about what we need to do at this park and the kind of park you wanted? Well guess what? It's being built," then community participants feel valued and "grateful to be invited."
Community health assessments and health improvement plans	Community health assessments and health improvement plans support health equity, either explicitly or implicitly, by identifying root causes of poor health and developing plans for addressing them. Through interviews, focus groups, and surveys, governments and organizations can gather input from communities about their most pressing challenges and strengths and ensure new programs are only implemented when the community asks for them. Further, community health assessments are often the first step in community engagement. As one interviewee noted after performing a community assessment, "We build relationships right from the get-go with all those assessment processes."
Community health workers	Many interviewees stated that community health workers are an important asset for community engagement; one interviewee said, "Community health workers doing direct outreach to their clients is our number one way of engaging people." Another

Example	Definition
	said, "They're really the ones who are able to reach people in their neighborhood because they're their peers and they understand what's going on." Through community health workers, organizations can learn about the barriers to accessing resources and services community members experience and gather feedback on improving upon and developing new programs. For instance, community health workers can screen clients for social determinants of health, providing data on community needs. Another interviewee described community health workers as playing a liaison role, stating, "Community health workers translate people to systems and systems to people. So, they help people understand how to better navigate through complex systems, but they also help those complex systems understand how to better serve the people that they should be serving."

Sources: Key stakeholder interviews.

In the following sections, we describe specific community engagement efforts undertaken by various stakeholders in our study states. The descriptions draw on our stakeholder interviews and organizations' and efforts' websites.

The Central Providence Health Equity Zone

The Rhode Island Department of Health's Health Equity Zones initiative provides funding and infrastructure support to local communities to design and implement health equity initiatives.[19] As described by one key participant, health equity zones pull together "a core group of stakeholders that will form a collaborative that will then conduct a comprehensive assessment and take the findings from that assessment, prioritize themes and topic areas, and then use that to develop a strategic plan to address social and environmental determinants" of health. Health equity zones also coordinate similar work between CBOs. Through tools such as direct investments and subcontracts, health equity zones fund local priorities identified by partner organizations and residents to improve health and well-being in their communities, providing a more nimble structure for addressing health equity challenges.

The Central Providence Health Equity Zone (CP-HEZ) covers the 02908 and 02909 zip codes, which include nine Providence neighborhoods: Elmhurst, Federal Hill, Hartford, Manton, Mount Pleasant, Olneyville, Silver Lake, Smith Hill, and Valley. ONE Neighborhood Builders serves as the backbone organization, or convening entity, for the CP-HEZ. ONE Neighborhood Builders is a community development corporation whose mission is to develop affordable housing and engage neighbors across Greater Providence to cultivate healthy, vibrant, and safe communities. The nonprofit coordinates the work of CBOs and individuals working to improve health equity in the area. It also solicits grants from the Rhode Island Department of Health, Fund for a Healthy Rhode Island,

and other organizations and agencies, which allows them to fund staff and programs. Much of this funding is passed on to CBOs through competitive requests for proposals that ONE Neighborhood Builders issues for health equity work in the CP-HEZ.

The CP-HEZ primarily engages with the community through regular community assessments and a team of community health workers who are all registered apprentices, learning their craft while earning a living wage. Some community health workers are employed by ONE Neighborhood Builders and some by partner organizations receiving funding through the CP-HEZ. Before starting any programs, all health equity zones must spend a year conducting neighborhood assessments, which allows them to build relationships with community members and assess the strengths and needs of the community. Just before the COVID-19 pandemic, the CP-HEZ hired direct service organizations in the community to conduct more than 375 in-person surveys with residents. Additionally, community health workers screen clients for social determinants of health, providing additional data on community needs. The representative we interviewed said that when creating and funding programs, the CP-HEZ seeks to promote work that addresses the root causes of health disparities.

The Colorado Trust, a Health Equity Foundation

The Colorado Trust is a foundation committed to supporting local, regional, and statewide efforts to advance the health and welfare of every Coloradan. Over the past decade, it has committed to achieving health equity, which it defines as ensuring all populations within Colorado have fair and equal opportunities to live healthy, productive lives regardless of race, ethnicity, income, or place of residence. This commitment resulted in new community engagement and a unique approach, resident-driven community grantmaking practices, which uses various community organizing principles and techniques to involve Coloradans in identifying and addressing health equity concerns in their own communities. The Colorado Trust's funding structure provides resources and technical assistance to teams of community members throughout Colorado to address the issues they prioritize. In some of their community partnerships, The Trust uses fiscal sponsors to handle administrative and fiscal responsibilities. Its staff members also help develop the capacity of resident teams, providing technical assistance and financial and organizational support for the community resident team members.

The Colorado Trust has worked to build and maintain authentic partnerships with resident teams in several Colorado communities. A foremost example of the organization's resident-driven community engagement approach involves language justice, or the idea that multilingual community members should be able to participate in their primary or native language.[20] Language justice allows

The Colorado Trust to engage with and include the diverse populations of Colorado, which include bilingual and non-English-speaking immigrants and refugees from around the globe, including speakers of Spanish, Somali, Swahili, and French. By focusing on multilingual Colorado residents and attempting to include as many Coloradans as possible, The Colorado Trust reportedly was able to authentically improve community confidence and involvement. For example, language justice was applied to a city council session, where the council engaged with community members in multiple non-English languages. Consequently, that city council now supports interpretation services. A representative of The Colorado Trust said that when designing its community partnership organizing strategy, the organization focused on language gateways to centralize their efforts on supporting those most marginalized.

The Columbia Gorge Health Council Community Advisory Committee

Oregon's Medicaid beneficiaries are enrolled in 1 of 16 coordinated care organizations (CCOs) operating in communities across the state.[21] CCOs are accountable care organization–like networks of different provider types that operate under global budgets to provide coordinated physical, behavioral, and dental services to Medicaid enrollees. Each CCO is contractually required to have at least one community advisory council (CAC),[22] on which more than half of voting members must be Medicaid enrollees.

The Columbia Gorge Health Council works as a partner to the PacificSource Community Solutions coordinated care organization in the Columbia Gorge region. The Columbia Gorge Health Council governs the CCO, allocates spending, and operates programs through the guidance of three committees: the CAC, community advisory panel, and board of directors. The Columbia Gorge Health Council attempts to engage community members where they live and work to gather feedback and invite them to participate in CAC meetings. One of the council's primary methods for community engagement is a strong network of community health workers who engage community members one on one to assess their needs and barriers to accessing services.

Columbia Gorge Health Council's monthly 40-person CAC meetings are alternately held in the two counties the CCO covers. The council provides a stipend and free transportation and child care for the CAC's 12 voting members. The CAC also provides translation and interpretation services and alternates presentations in English and Spanish as much as possible, meaning the CAC flips who is

being translated to. The CAC also attempts to make participants feel comfortable sharing their thoughts and experiences by creating an atmosphere of what one interviewee described as "organized chaos" that aims to make conversations more natural and comfortable. Through these methods, the CAC has developed a strong relationship with PacificSource, in which the CAC provides community input and PacificSource reports back on the steps it is taking to act on the community's advice.

My Brother's Keeper Inc.

My Brother's Keeper Inc. (MBK) is a private, nonprofit CBO that aims to reduce health disparities in Mississippi by enhancing the health and well-being of marginalized populations. First established to provide treatment and prevention services to people living with HIV/AIDS, MBK's focus has expanded to include health conditions that disproportionately affect communities of color, uninsured and underinsured people, and underserved populations, such as those with diabetes, heart disease, obesity, and cancer. MBK's strategies include health education, health promotion, policy and environmental systems changes, and other health equity approaches.

To meet the multifaceted needs of the diverse communities it serves, MBK has an organizational structure with three divisions: (1) the Center for Community-Based Programs, where culturally effective prevention training activities take place in response to problems identified by communities; (2) the Center for Research, Evaluation, and Environmental Policy Change, which focuses on developing an evidence base for equitable policy; and (3) Open Arms Healthcare Center, the first and only LGBTQIA+ population–focused primary health care clinic in Mississippi. In addition, MBK offers capacity-building services, such as research and development, quality improvement, and training services, to organizations nationwide. MBK's programs and initiatives prioritize African American Mississippians and people who identify as LGBTQIA+, though they also serve heterosexual women and men. Examples of their programs and services include men, women, and transgender health programs, family planning services, on-site mental health programs supported by case managers, an on-site food pantry, transportation services, an on-site pharmacy, and a multiregional TelePrEP program, which allows clients to access PrEP (pre-exposure prophylaxis), the HIV-prevention medication, without a clinic visit using a computer or smartphone.

MBK's approach to care is unique in that it is employs multiple strategies to center and engage the community. It intentionally hires people from the community it serves to both represent community voices and facilitate trust and relationship building with community members. In addition, MBK proactively requests feedback and participation from community members to develop

responsive programming and conduct assessments of their planned programmatic operations. It also relies on the information provided by staff and community members to develop services and programs that can benefit their communities. MBK provides gift cards and transportation to community members to engage them. As a professional mantra, MBK teams believe that "we do not extract anything from the community and we believe in paying people for their time," as one MBK interviewee said. In 2019, Mississippi had the highest national percentage of people who had incomes below the poverty line. With such high poverty rates and related food insecurity rates, MBK considers incentives modest compensation for the priceless information community members provide during program implementation and research.

"We are in an impoverished state, so [program participants] deserve [at least] $50 and a meal," an MBK team member shared. They added, "We do it properly by honoring and acknowledging that this person's information is valuable, and it's not something that can be given to you for free ."

Appendix B. Selected Community Engagement Resources

As noted, resources for engaging with communities are becoming more prevalent and accessible. The below examples provide more information and practical guidance for governments, health care and social service organizations, philanthropies, and others interested in implementing community engagement initiatives.

Authentic Community Engagement to Advance Equity
Colorado Department of Health and Environment, Office of Health Equity
https://www.colorado.gov/pacific/sites/default/files/Authentic-Community-Engagement-to-Advance-Equity.pdf

Community Engagement
Racial Equity Tools
https://www.racialequitytools.org/resources/act/strategies/community-engagement

Community Engagement during the COVID-19 Pandemic and Beyond: A Guide for Community-Based Organizations
Martha Fedorowicz, Olivia Arena, and Kimberly Burrowes (Urban Institute)
https://www.urban.org/research/publication/community-engagement-during-covid-19-pandemic-and-beyond

Community Engagement Guide
Washington State Department of Health
https://www.doh.wa.gov/Portals/1/Documents/1000/CommEngageGuide.pdf

Community Engagement Strategy and Communications Plan: 2018–2024
Jackson Heart Study Community Engagement Center
https://www.jacksonheartstudy.org/Portals/0/images/Community/CECCESPlan.pdf?

Engage the Community
Centers for Disease Control and Prevention
https://www.cdc.gov/chinav/tools/engage.html

Health Equity Zones: A Toolkit for Building Healthy and Resilient Communities
Rhode Island Department of Health
https://health.ri.gov/publications/toolkits/health-equity-zones.pdf

Participatory Grantmaking: Has Its Time Come?

Cynthia M. Gibson (Ford Foundation)

https://www.fordfoundation.org/media/3598/has-the-time-come-for-participatory-grant-making.pdf

Principles of Community Engagement, 2nd ed.

Clinical and Translational Science Awards Consortium Community Engagement Key Function
Committee Task Force on the Principles of Community Engagement

https://www.atsdr.cdc.gov/communityengagement/pdf/PCE_Report_508_FINAL.pdf

Why Am I Always Being Researched?

Chicago Beyond

https://chicagobeyond.org/researchequity/

Notes

1   "Tracking COVID-19's Effects by Race and Ethnicity: Questionnaire Two," Urban Institute, updated May 24, 2021, https://www.urban.org/features/tracking-covid-19s-effects-race-and-ethnicity-questionnaire-two; and Mark Hugo Lopez, Lee Rainie, and Abby Budiman, "Financial and Health Impacts of COVID-19 Vary Widely by Race and Ethnicity," Pew Research Center, May 5, 2020, https://www.pewresearch.org/fact-tank/2020/05/05/financial-and-health-impacts-of-covid-19-vary-widely-by-race-and-ethnicity/.

2   National Governors Association, memo to governors' offices, regarding "Reducing the Disproportionate Impact of COVID-19 among Communities of Color," June 25, 2020, https://www.nga.org/center/publications/impact-covid-19-communities-of-color/; "COVID-19 Health Equity Initiatives across the United States," American Medical Association, accessed May 28, 2020, https://www.ama-assn.org/delivering-care/health-equity/covid-19-health-equity-initiatives-across-united-states; and Allie Atkeson and Rebecca Cooper, "States Address Racial and Ethnic Disparities in their COVID-19 Responses and Beyond," National Academy for State Health Policy, March 22, 2021, https://www.nashp.org/states-address-racial-and-ethnic-disparities-in-their-covid-19-responses-and-beyond/.

3   "Executive Order on Ensuring an Equitable Pandemic Response and Recovery," the White House, January 21, 2021, https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/21/executive-order-ensuring-an-equitable-pandemic-response-and-recovery/; Centers for Disease Control and Prevention, "CDC Announces $2.25 Billion to Address COVID-19 Health Disparities in Communities That Are at High-Risk and Underserved," news release, March 17, 2021, https://www.cdc.gov/media/releases/2021/p0317-COVID-19-Health-Disparities.html; and "COVID-19 Health Equity Initiatives: Black Arizona COVID-19 Task Force," American Medical Association, accessed May 28, 2021, https://www.ama-assn.org/delivering-care/population-care/covid-19-health-equity-initiatives-black-arizona-covid-19-task.

4   Atkeson and Cooper, "States Address Racial and Ethnic Disparities in their COVID-19 Responses and Beyond," National Academy for State Health Policy; and Alexis Butler, Katherine Carter, and Lauren Lowery, "Embedding Racial Equity in Housing," National League of Cities, July 9, 2020, https://www.nlc.org/article/2020/07/09/embedding-racial-equity-in-housing/.

5   In this report, we use "community-based organization" (CBO) to refer to trusted, community-based, culturally effective programs and organizations that serve and/or advocate on behalf of historically disadvantaged and marginalized communities, including people of color, Native Americans, immigrants, people with disabilities, those who identify as LGBTQIA+, people who experience homelessness, people involved in the criminal justice system, and uninsured or publicly insured people. These organizations may include community health centers, immigrant-serving organizations, social service providers, faith-based institutions, and grassroots advocacy groups.

6   "Tracking COVID-19's Effects by Race and Ethnicity: Questionnaire Two," Urban Institute; and Lopez, Rainie, and Budiman, "Financial and Health Impacts of COVID-19 Vary Widely by Race and Ethnicity," Pew Research Center.

7   National Governors Association, memo to governors' offices, regarding "Reducing the Disproportionate Impact of COVID-19 among Communities of Color;" "COVID-19 Health Equity Initiatives across the United States," American Medical Association; and Atkeson and Cooper, "States Address Racial and Ethnic Disparities in their COVID-19 Responses and Beyond," National Academy for State Health Policy.

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13 "What Is Systemic Racism? [Videos]," Race Forward, accessed May 28, 2021, https://www.raceforward.org/videos/systemic-racism; and "Structural Racism in America," Urban Institute, accessed May 28, 2021, https://www.urban.org/features/structural-racism-america.

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17 "Executive Order on Advancing Racial Equity and Support for Underserved Communities through the Federal Government," the White House, January 20, 2021, https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/; and Abigail Painchaud, "OMB Issues RFI on Equity across the Federal Government," America's Essential Hospitals, May 17, 2021, https://essentialhospitals.org/policy/omb-issues-rfi-equity-across-federal-government/. See also Gaynair, "Participatory Grantmaking Aims to Dismantle Power Imbalances between Funders and the Communities They Serve," *Urban Wire*.

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