Community-based participatory research (CBPR), which uses a community-centered approach to data gathering and translation, can significantly improve the “relevance, rigor and reach” of data-driven practices. Engaging community members in problem definition, data collection, analysis, and design of interventions can ensure that data-driven practices are culturally meaningful, valid, and appropriate. It can also help build the capacity of both individuals and the community to study and address health and social issues of local concern. While not without challenges, CBPR is a critically important approach to use when working in historically marginalized and vulnerable communities.
ENHANCING DATA QUALITY, RELEVANCE, AND USE THROUGH COMMUNITY-BASED PARTICIPATORY RESEARCH

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The past two decades have witnessed growing calls for research conducted with—rather than on—communities. Researchers themselves have often voiced frustration with the limitations of traditional “outside expert-driven” research for gathering data and developing evidence-based interventions to address complex health and social problems. Meanwhile, calls from National Institutes of Health (NIH), the Institute of Medicine, and other government bodies, foundations, and communities for research that is “community based,” not simply “community placed,” have stimulated the movement toward new, community-engaged approaches to data gathering and translation. Long-standing distrust of outside researchers doing “parachute research”—dropping in, collecting data, disappearing, and leaving nothing behind—has also necessitated a new, more culturally sensitive orientation to research.¹ This is the case particularly in low-income communities of color, which sometimes refer to academic researchers as “the real undocumented workers.”

Yet another reason exists for the increasing attention to research that actively engages local residents and other partners: Communities often have sophisticated insider knowledge and understanding that allow researchers to ask the right questions and gather data in ways that will increase the “relevance, rigor and reach” of the findings to effect change.²

² C. L. Balazs and R. Morello-Frosch, “The Three Rs: How Community-Based Research Strengthens the Rigor, Relevance, and Reach of Science,” Environmental Justice 6 (1) (2012): 9–16.
DEFINITION AND CORE PRINCIPLES

Community-based participatory research (CBPR) is concisely defined as “systematic investigation, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting change.” Drawing on the work of Barbara Israel at the University of Michigan and her community and academic partners, the core principles of CBPR include (1) recognizing the community as a unit of identity; (2) emphasizing community strengths; (3) ensuring the research topic is important to the community; (4) engaging community members throughout the research process; (5) facilitating community capacity building and systems change; and (6) balancing research and action. In addition, CBPR should explicitly include attention to gender, race, class, and culture. These factors interlock and influence every aspect of the research enterprise. The concept of “cultural humility” is particularly useful for recognizing and helping address the privilege and unintentional biases researchers may bring to a CBPR effort. Developed by Melanie Tervalon and Jane Garcia, cultural humility suggests that while researchers can never be “competent” in another’s culture, they can demonstrate openness to learning about other cultures while examining their own biases, addressing power dynamics, and committing to authentic partnership.

CBPR occurs on a continuum. Applications range from the use of community advisory boards (CABs) to help with sample recruitment or other specific tasks, to the more emancipatory end of the continuum with its emphasis on community engagement throughout the processes.


of data collection, data interpretation, and data-based action for change. Increasing efforts are made in both government-and philanthropic-funded university partnerships and grassroots community-led partnerships to meet the gold standard of CBPR, with genuine, high-level community engagement occurring throughout the process.

HOW COMMUNITY-BASED PARTICIPATORY RESEARCH IMPROVES DATA COLLECTION, ANALYSIS, AND USE

CBPR can add value to data collection, relevance, and use in multiple ways. Here, I examine specific advantages of this community-partnered approach for improving data and research, using “real world” examples to illustrate each point.

Source and Relevance of Research Questions

CBPR helps ensure that the research question comes from—or is of genuine concern to—the community. When funding sources mandate research on particular health or social problems, or when researchers in academia, government, or the private sector decide in advance the topic to be studied as it relates to a particular community, valuable data may be produced. But that data may be irrelevant to genuine concerns of community residents. Consequently, the findings may be used to develop and deploy interventions that achieve modest results at best, partly because of lack of community interest or uptake. In contrast, when communities are actively engaged in identifying a problem they believe is relevant, their involvement with the study will be greatly improved. Furthermore, community engagement ensures greater likelihood that the findings will be both useful and translatable into changes in programs, practices, and policies that benefit the community.

Getting it right. In the early 1990s, residents of Harlem strongly suspected a link between the area’s high rates of childhood asthma and the presence of seven of the eight city bus depots, in addition to

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numerous other polluting facilities. A local organization, West Harlem Environmental Action (WE ACT; www.weact.org) reached out to an epidemiologist at the Mailman School of Public Health at Columbia University to study this problem. The resulting partnership used air monitoring and geographic information systems (GIS) mapping as key data collection methods. Their studies, conducted in part with WE ACT’s high school-aged “Earth Crew” youth, led to high-quality data. These data helped achieve a number of important policy outcomes, including stricter air quality standards, which withstood all legal appeals, and the conversion of all city buses to clean diesel. The respect shown for community identification of need also formed the basis of a long-term collaboration. After more than 16 years, partnership continues and the community partner has occasionally been the recipient of federal grants, which are subcontracted to the university partner. Had the researcher at Columbia failed to acknowledge the wisdom of the community’s concern with asthma and diesel pollution, this long and highly successful partnership would likely never have taken shape.

Acceptability of Data and Data Collection Tools
CBPR can improve the cultural acceptability of data collection tools, often enhancing their validity and the utility of the data collected. Data collection instruments that reflect lack of familiarity with acceptable terms and local concerns often result in lower participation rates and data of questionable value. For example, although the notion of empowerment is central to CBPR, no single word in Spanish captures this concept and, indeed, many Spanish terms with power at their center refer to “power over,” not “power to” or “power with,” and thus completely miss the true meaning of this term. Similarly, data instruments referring to a community by its official name may miss the common and deeply valued local designations of a neighborhood and reinforce the lack of cultural and social familiarity of outside researchers. We can learn from community partners for more successful and effective data gathering and use. Community partners teach us how


10 Ibid.
to refer to particular health or social conditions in a local community. In addition, they teach us whether individual interviews, focus groups, secondary data analysis, air monitoring, or other data collection methods may be most acceptable and useful.

**Getting it right.** Partnering with the local Chinese Progressive Association and the hiring and training of six immigrant restaurant workers in the Chinatown Restaurant Worker Health and Safety Study in San Francisco resulted in substantial improvements to both a detailed survey instrument and a new restaurant observational tool that the health department partner used to assess restaurant health and safety from a worker perspective, and not merely that of a customer. The final data collection instruments enabled the gathering of detailed data from 433 individual workers and all but two of Chinatown’s 108 restaurants. Policymakers later credited the data as contributing substantially to the city’s passage and implementation of one of the nation’s first wage theft ordinances.\(^\text{11}\)

**“Ground-Truthing”**
Community members can also play a key role in “ground-truthing,” or checking the validity of existing government or other data sets.\(^\text{12}\) Although many scientists rely on government data sets and conduct secondary data analysis on problems such as air or water pollution, these data sources are often dated and flawed. The quality and utility of data sets can be improved with assistance from the community in checking the accuracy of the data sets and using area “walk-throughs” with maps and/or tablets and GIS devices.

**Getting it right.** Using government GIS maps of stationary toxic pollution emitters and “sensitive receptor land uses” (e.g., schools, day care centers, and other places where residents are likely to be particularly sensitive to such emissions), residents in California’s San Fernando


Valley and other areas have successfully “ground-truthed.” They performed the process by walking through neighborhoods with existing data sets and using their observations “on the ground,” in addition to their lay knowledge of new facility closings or openings, etc., to provide substantially better and more up-to-date data than the data on which government offices and decision makers had previously relied. In the San Fernando case study, residents also found a number of previously unnoted sensitive receptor land uses, which they added to what is now a much more accurate data set.\textsuperscript{13}

**Design and Implementation of Data-Driven Interventions**

Community engagement can improve the design and implementation of data-driven interventions, increasing the likelihood of success. Outside expert-designed interventions often reflect little knowledge of local customs and beliefs. Resulting interventions may be doomed to fail, often at substantial cost. Numerous multiyear, multimillion dollar research efforts to address problems such as tobacco control in low-income communities have attempted community engagement. However, these efforts were largely designed and implemented by outside experts. As public health leader S. Leonard Syme and others have noted, the results have tended to be disappointing, and community distrust of outside researchers has often been reinforced in the process.\textsuperscript{14}

**Getting it right.** A cluster-randomized, controlled trial was conducted in California’s Salinas Valley to test interventions aimed at reducing children’s exposure to pesticide residue brought home on the clothing etc. of their farmworker parents.\textsuperscript{15} Yet two of the interventions never would have succeeded had it not been for the input of farmworker members of the project’s Community Advisory Board (CAB). For example, when CAB members were asked about the proposed addition of hand washing stations in the fields, they pointed out that in their Mexican culture, washing hands in cold water was believed to cause arthritis. With that

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\textsuperscript{13} Ibid.


information, the proposed intervention was redesigned to include water heaters, and hand washing rates at lunch time and before going home significantly improved. Respect for community wisdom also helped build the trust that has enabled more than a decade of additional data gathering from this community, including current policy-focused interventions and an environmental health youth leadership program.

**Data Interpretation**

Community-engaged research can improve data interpretation. Outside researcher interpretation of data based solely on scientific approaches, and lack of familiarity with local cultures and contexts, can lead to misunderstanding of the data, decreasing its usefulness and sometimes leading to flawed program recommendations and policy.

*Getting it right.* The East Side Village Health Worker Project, a partnership between Detroit community-based organizations and academic partners at the University of Michigan, Ann Arbor, trained and actively engaged village health workers (VHWs) in collecting and interpreting data from a random household sample of more than 700 residents. Although the academic partners were surprised to find overall resident satisfaction with access to care, the VHWs quickly explained that quality of care was a far greater concern than access to care in this low-income neighborhood, whose members sometimes had access to government programs or clinics for the poor, but of less-than-adequate quality. Similarly, in the Chinatown study, trained worker partners participated in weekly data interpretation workshops. Their many contributions included pointing out that the high proportion of workers reporting that they received “paid sick leave” (42 percent) was likely inflated. This figure reflects the fact that for many in this community, paid sick leave simply means having the ability to take a day off when ill or caring for a sick relative and making it up later with an extra day’s work without pay.

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16 Ibid.


19 Chang et al., "Popular Education,” Minkler et al. "Wage Theft.”

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New Channels for Data Dissemination

Engaging community partners in research can help identify and use new channels for data dissemination. Canadian scholar and activist Dennis Raphael is fond of asking, “If an article is published in *Social Science and Medicine* but nobody reads it, does it exist?” Although the importance of traditional academic and professional vehicles for disseminating findings cannot be minimized, community partners can play an important role in determining how best to reach the community “end users” of data, relevant organizations, and policymakers.

Getting it right. In the Harlem case study mentioned earlier, the data generated on asthma and diesel exposure were both scientifically sound and deeply troubling. Although the academic partner took the lead in submitting jointly authored articles to peer-reviewed journals, the community partner used numerous other avenues to “get the word out” to the local community and policymakers. Seventy-five bus shelter ads, an alternative fuels summit, legislative briefings and testimony, and articles in a community newspaper were among the methods used. WE ACT also conducted “toxic and treasure tours” for local policymakers—highlighting not only toxic exposures but also the rich cultural heritage of the neighborhood, with landmarks such as the Apollo Theater and its pivotal role in the history of jazz. This dissemination of findings did not preclude subsequent publication of more detailed analysis. But it did help jump start the process of data-driven community organizing and advocacy and helped effect many significant policy changes.

Improving Public Policy

Community-engaged research can help in the use of data to improve public policy. Many academic and other researchers develop reliable data with substantial policy and practice relevance but believe that using that data to help inform action for change is outside their purview. With its emphasis on action as part of the research process, and the credibility it has achieved with numerous public and private sector sources, CBPR can help legitimize the role of researchers, as part of a

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20 Shepard et al., “Using CBPR to Promote Environmental Justice.”
partnership, in ensuring that data are used to effect positive community and social changes.

**Getting it right.** For many incarcerated men, leaving jail or prison is a “round trip,” and in some areas, close to one-half of newly released prisoners are back in custody within a year.\(^{21}\) A community-academic partnership in New York City collected extensive data on this situation through multiple methods, including secondary data analysis, public opinion polls, focus groups, policy analysis, and interviews with social service providers and recently incarcerated men. Through these multiple means, they uncovered 11 state policies that worked against staying out of jail. These included the common practice of releasing men after midnight with a bus ticket back to the community where they were arrested in the first place. In addition, policy included terminating rather than temporarily suspending, their access to Medicaid, meaning that those with substance abuse, other mental health problems, or physical conditions such as HIV/AIDS, were unable to receive the help they needed on release. By working together beyond the funded project period, academic/activist Nicholas Freudenberg, his community, and other partners used these data to help change these and other policies citywide.\(^{22}\) Other communities have followed their example.

**Building Individual and Community Capacities**

Engaging community partners in research can help build individual and community capacities, leaving behind a community more able to study and address other health and social issues of local concern. One of the greatest benefits of CBPR is, arguably, its contributions to increasing critical thinking, individual and collective problem-solving abilities, civic engagement, and future orientation among participants—particularly those from marginalized communities. Sometimes called “street science,” CBPR is a means of democratizing the collection and use of data and in the process increasing active citizenship and local leadership.\(^{23}\)

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22 Blackwell et al., “Using Community Organizing and Community Building to Influence Public Policy.”

Getting it right. In Old Town National City, a once-vibrant heart of the Latino community in San Diego County, California, rezoning as a mixed use neighborhood led to skyrocketing asthma rates as the community was overrun by auto body and paint shops and other polluting businesses.\textsuperscript{24} The local Environmental Health Coalition (EHC) hired and trained Latinas as lay health advocates, or promotoras, to help study and address this problem. The promotoras learned to do door-to-door surveys and to measure ultrafine particulate matter, which academic colleagues recently had shown to be related to adverse lung development in children.\textsuperscript{25} At the same time, the promotoras also learned public speaking, media advocacy, and “data language,” including how to present both their findings and those from GIS-based “visual footprints” developed by EHC staff, to capture the huge disparities in toxic emissions exposure between their community and three adjacent footprints. The promotoras used role playing and follow-up debriefings to improve their presentations before City Council hearings and in private testimony. They learned to do base building, recruiting many other local residents to become civically active. The work of the promotoras and their partners was given much of the credit for helping pass a Specific Plan in 2010, restoring the community to resident-friendly uses. Additionally, many of the promotoras continued their high-level civic engagement in other issues of concern. One of these women not only successfully ran for city council but became Old Town National City’s vice mayor, a position she continues to hold at this writing.\textsuperscript{26}

**CHALLENGES AND LIMITATIONS IN COMMUNITY-BASED PARTICIPATORY RESEARCH**

Although I have stressed the many ways in which CBPR can improve data collection, interpretation, and use to effect change, this approach can be messy, time consuming, and fraught with challenges.


Time and Labor-Intensive Nature of the Work

Building and maintaining partnerships take substantial time both early on and throughout the research and action processes. This often is compounded when working with youth, low-literacy groups, or immigrant workers who frequently work long hours and return home to serve as primary caregivers across generations. Translation costs and time delays, and the extra training time needed when working with partnerships that vary dramatically in education, social class, and racial/ethnic background add to the time and costs incurred. Finally, as highlighted earlier, the call to include action as part of the research process itself often requires the engagement of outside researchers and their partners well beyond the funded project period.

In the community reentry project for men recently released from incarceration in New York City, many of the most significant policy victories occurred after the funded project period had ended. Similarly, in the Chinatown case study, policy-level change to address rampant wage theft among restaurant workers took place, in part, because project partners continued to work with policy allies at city hall to help craft and achieve passage of two new pieces of legislation after the project funding had ended. This work, and the resulting wage-theft ban and enforcement measure, contributed substantially to the subsequent record levels of recovered wages in Chinatown and other parts of the city as well.

Conflicts and Power Dynamics

Conflicts and power dynamics are a challenging but necessary part of community-engaged research. Civil rights leader Bernice Regan once remarked that if a coalition is too comfortable, you probably do not have a very good coalition. Similarly, in CBPR, partners should include groups that do not see eye-to-eye on all issues but who share a commitment to the topic being studied and are willing to deal with conflict. Struggles for power, the just allocation of resources, and elements of the study design and implementation are parts of the process itself. Developing initial ground rules, principles of engagement, and

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27 Blackwell et al., “Using Community Organizing and Community Building to Influence Public Policy.”
28 Chang et al., “Popular Education”; Minkler et al., "Wage Theft."
memorandums of understanding (MOUs), as well as ongoing evaluation and feedback, may help address these concerns early. Having a partnership evaluator or evaluation subcommittee, and using guiding criteria and rating scales to assess partnership adherence to CBPR principles and best practices, may also help the partnership stay on track and confront and address difficult issues as they arise.\textsuperscript{29}

**Ethics Committees and Institutional Review Boards**

Ethics or institutional review board (IRB) processes and criteria typically are not well aligned with the principles and processes of community-engaged research. Requirements that the principal investigator (typically a university-based partner) assume overall responsibility for major project-related decision-making is antithetical to CBPR, with its emphasis on shared power and equitable participation of all partners in project-related decision-making. Similarly, IRBs seldom are comfortable with the extensive ongoing community involvement in data collection and use that CBPR projects can entail—a problem that commonly can lead to long delays in IRB clearance.\textsuperscript{30}

Educating IRBs on CBPR can help address this process, and a small but growing number of universities have created IRB subcommittees specifically trained to evaluate community-engaged research proposals. Yet the continued mix-match between principles of CBPR and the requirements for IRB approval often remains a substantial hurdle. Sarah Flicker at York University and her colleagues in Toronto\textsuperscript{40} have developed a helpful set of guidelines for IRBs as they review community-engaged research projects.\textsuperscript{31} These criteria stress community, not only individual-level risks and benefits of research proposals. Included among their guidelines are questions such as: How was the community involved or


consulted in defining the need?; How will the project balance scientific rigor and accessibility?; and, Are there built-in mechanisms for dealing appropriately with unflattering results? Partnerships themselves can also benefit from using these tools and discussing these issues well in advance of data collection, which brings up a related question: What will be done if findings do not support the action agenda, which the community partner may be hoping to pursue?

In a CBPR project between academic partners and hotel workers and their union in San Francisco, a preliminary agreement was made that findings would be published, even if the findings did not support the workers who hoped to show that lean staffing and pressure to work more quickly had adversely affected their health. Fortunately in this case, the data strongly supported their position and were successfully used in contract negotiations, with the outside researcher and worker partners at the bargaining table to help make the case for reductions in work load.\(^\text{32}\) But the opposite could have happened, and having agreements in place early on about how data will be used can help avoid tensions later.

**Scientific and Community Concerns Regarding Data Collection and Interventions**

Tradeoffs exist between scientific priorities and community concerns regarding data collection and data-driven interventions. The enhanced cultural sensitivity and relevance of research instruments made possible by high-level community collaboration may also, at times, conflict with outside research partners’ desires for the most rigorous possible research designs and study instruments. Community partners may question the relevance of certain validated scales or may oppose, on the grounds of fairness, a randomized controlled study, given that not all participants stand to gain from a potentially useful intervention. Approaches such as a staggered research design, in which control group members do receive the intervention, albeit not as early as the treatment group, may help address these concerns but may not fully satisfy some community partners who are anxious to see widespread local benefit from their participation.

Timelines for Data Sharing
Tensions exist between the “necessary skepticism of science” and the “action imperative of the community” with regard to data sharing and use. Public health leader Richard Hofrichter points out the mixed messages frequently given by academic researchers: “What do we want? Evidence-based policy! When do we want it? After peer review!” Community partners may wish to move more quickly from findings to action, including advocating for change, whereas research partners may wish to move more slowly, conducting further data checks to ensure the accuracy of any findings put forward and, in some cases, waiting for peer review and publication of findings. Moreover, some scientific journals require that results not be shared before their publication. Yet asking community partners to wait for what may often be two to three years before sharing data that could help move programs, policies, and practices does not keep with the fundamental commitments of CBPR. A growing number of top-quality journals now publish CBPR and understand that some key findings may indeed have been shared with primary stakeholders in advance to help promote change. Although some journals continue to have editorial policies stating that recommendations for policy and other changes should be omitted and placed instead in commentaries and letters to the editor, these are not appropriate venues for the publication of community-engaged work.

As noted earlier, data also may emerge, which could show the community in an unflattering light and which community partners do not want to have “go public.” Continued dialogue and MOUs may be helpful in anticipating these uncertainties and deciding on ways to deal with them early on, but these methods are not likely to preclude unanticipated issues regarding data ownership and use from arising. Such issues will require the utmost care as they are addressed.

SUMMARY AND CONCLUSIONS
CBPR involves many challenges, from the substantial time and labor involved through the compromises that must sometimes be reached regarding data collection methods and other key aspects of the work.

These challenges may be intensified when partnering with marginalized groups, often with low educational levels, limited command of the dominant language, and severe time and income constraints. Yet, the potential of CBPR for improving the “relevance, rigor and reach” of data, and for building individual and community capacity, is increasingly seen as outweighing the challenges involved. Community engagement clearly is not appropriate for all forms of research. However, when it is appropriate, working collaboratively with community partners in the research process can improve a particular research endeavor. It can also help to further increase the democratization of data collection and use as we continue progressing into the 21st century information age.

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34 Balazs and Morello-Frosch, “The Three Rs.”