

Community-based Participatory Research Is Needed to Address Pulmonary Health Disparities

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Abstract

Socioeconomic and racial disparities in the outcomes of medical management remain common across pulmonary diseases in the United States and worldwide. Acknowledging this, the American Thoracic Society recently put forth recommendations to advance respiratory health equity. Through engagement of vulnerable communities in search of collaborative solutions to improve health disparities, community-based participatory research embodies concepts essential to the American Thoracic Society mission for respiratory health equity. The purpose of this commentary is to provide an overview of the principles of community-based participatory research and the application of this approach to addressing inequity in the outcomes of treatment for lung disease. Community-based participatory research aims to decrease health disparities by recognizing the social and ecological paradigms of health care and by partnering community members with academic researchers in all aspects of the research

process. Community partners are uniquely poised to offer insight into local culture, circumstances that guide health behaviors, and other challenges to improve their own community's health. Sustainable interventions, either through strengthening existing community assets or through community empowerment and local capacity building throughout the research process, are essential to the success of community-based participatory research. The National Institutes of Health and other funding agencies offer funding opportunities to support specific interventions aimed at engaging community members in the research process. In pulmonary medicine, community-based initiatives have focused primarily on improving pediatric asthma outcomes. Using a community-based approach in adult asthma and other pulmonary diseases could be an ideal manner in which to decrease pulmonary health disparities.

Keywords: community-based participatory research; community engagement; health disparities; social determinants of health

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Despite new and improved treatment options for many pulmonary diseases, socioeconomic and racial disparities in risk factors, access to care, and outcomes are common. A classic example is the case with asthma; treatments are well established but there are racial and socioeconomic disparities in exposure to environmental triggers (1, 2), management, and outcomes (3). In this context, the American Thoracic Society (ATS) recently created a Health Equity Subcommittee to

define respiratory health disparities and provide recommendations to the ATS leadership for facilitating the attainment of respiratory health equity in the United States.

Recommendations included promoting scientific inquiry and training, especially related to health disparities; disseminating medical information and best practices; advocating for environmental justice and a healthy lifestyle for all; and diversifying the

workforce (4). Although not specifically named within the ATS recommendations, community-based participatory research (CBPR) embodies concepts essential to the ATS mission for respiratory health equity. The purpose of this commentary is to provide an overview of CBPR principles and to highlight examples of CBPR initiatives that address pulmonary diseases to demonstrate the usefulness of CBPR in addressing the inequity in pulmonary disease outcomes.

What Is Community-based Participatory Research?

In its purest form, CBPR is an approach to research that engages the community in all stages of research and puts academic researchers and community members on equal footing. CBPR can be used to approach any research design ranging from qualitative studies to randomized clinical trials. The core principles of CBPR include colearning, long-term partnerships, capacity building, community empowerment, and building sustainable systems (5). Community members and academic researchers are partners in all stages of research including hypothesis generating, grant writing, protocol development, data collection and analysis, and dissemination of findings. CBPR aims to create sustainable projects building on the capacity of the community and empowering its members. In prioritizing community action, a goal of CBPR is to disseminate the research results to the affected community and policy makers, and not just to members of the medical community (6). In several ways, CBPR is distinct from traditional, “community-placed” research, in which a community is necessary for the conduct of research but is not an engaged partner (Table 1).

Although CBPR has gained acceptance among academic researchers in the past decade only, pulmonary researchers used CBPR principles much earlier. A prime example is Irving J. Selikoff, a physician,

researcher, and vocal public advocate, who documented the adverse health effects of asbestos and advocated for a reduction in asbestos exposure, worker health and safety, and compensation for those with asbestos-related disease. Starting in the 1960s, he engaged insulators and shipyard and other asbestos-exposed workers to participate in clinical and epidemiologic studies and noted high rates of mesothelioma, lung cancer, and asbestosis. Dr. Selikoff also noted that the carcinogenic potential of asbestos was augmented when combined with cigarette smoking and was instrumental in promoting smoking cessation, in addition to advocating for reducing workplace exposures to asbestos (6). He disseminated these findings to the scientific community, as well as to workers and the public through unions and the media. His research and advocacy led to federal regulations protecting workers and the public from asbestos-related morbidity (7, 8). As demonstrated by Dr. Selikoff’s historical example, CBPR aims to decrease health disparities by incorporating social and ecological health paradigms into the research process.

Partnerships in Community-based Participatory Research

In the fullest expression of CBPR, community and academic partners each contribute to developing, conducting, and

disseminating research addressing collectively identified issues (5, 9). CBPR teams often partner with a community advisory board, usually composed of community members who represent community perceptions, preferences, and priorities (10). Examples of community partners in CBPR include community health centers, schools, public health departments, prisons, and neighborhood organizations.

Effective CBPR projects often build on existing relationships and efforts within the community (11). Community partners can offer unique insight into a neighborhood, local culture or traditions, circumstances that guide behaviors, and other challenges to improve their own community’s health (12). By asking a community to identify salient issues to address, rather than using the traditional research approach in which a researcher’s agenda might not reflect a community’s needs, CBPR encourages community engagement and enthusiasm for research (13) and greater relevance of the research to the community’s needs (14). Through engaged community partnerships, researchers are uniquely posed to recognize community assets and uncover local barriers to improve health outcomes (15).

Sustainability

Sustainable interventions are an important component of CBPR, whether through the

Table 1. CBPR vs. community-placed research

	Community-placed Research	CBPR
Goals	To generate new knowledge	Research is a vehicle for immediate action To decrease health inequities
Agenda setting	Academia	Collaborative effort between academia and community
Primary emphasis	Advancing science to improve health Publication	Action to improve health Empowering the community Sustainability
Expertise	Academia	Academia and community
Level of community participation	Mostly subjects; may aid in recruitment	Engaged partners throughout the research process
Dissemination	Primarily through publication to the medical community	To the affected communities, policy makers, health advocacy groups, and the medical community
Sustainability	Not a focus	Necessary for success
Funding	Grants written by researchers; funds go to researchers	Shared grant writing Equitable compensation
Added challenges	None	Building trusting relationships Data sharing/management Engagement of a vulnerable community Time intensive

Definition of abbreviation: CBPR = community-based participatory research.

strengthening of existing programs or by building on community assets (16). The processes of community empowerment and local capacity building can lead to lasting influence on a community's health-promoting resources (12).

CBPR can be an effective tool to influence health policy and promote a broader and more sustained effect on health. Together, academic researchers and community leaders can advocate policy change through disseminating evidenced-based programs or interventions that are cost effective and health promoting. Community leaders are uniquely qualified to educate policy makers about the local context and relevance of and experience with specific interventions aimed at health equity. CBPR partnerships can mobilize and organize larger community efforts to advocate for the social and economic policy change needed to address health disparities (17, 18).

Dissemination

In traditional research, academics engage a community while recruiting research subjects, disseminate their knowledge to the academic or medical community, and provide limited direct benefits to the community they have engaged (19). In contrast, dissemination strategies in CBPR are designed to promote multifaceted action to establish social change and improve health disparities directly in the studied community. Dissemination of CBPR results targets key individuals including policy makers, affected members of the community, and advocacy groups (20). Examples of CBPR dissemination techniques include using a local movie theater screen to communicate aggregate results, conveying research results with cultural symbols in conjunction with graphical data (21), and displaying educational messages on public art murals (22). Community partner input into dissemination strategies helps ensure the local relevance and cultural sensitivity of the presented information. In addition, community engagement in dissemination helps ensure that the health message is not perceived as judgmental or critical (21). Table 2 illustrates an overview of CBPR initiatives focused predominantly on pediatric asthma, in which community-academic partnerships,

outcomes, and community-level innovations are described.

Ethics

Marginalized communities, including people of color and people living in poverty, have a history of being exploited by research; the Tuskegee Syphilis Study is only one such example (23). Ongoing fear of exploitation and mistrust of academic institutions remain in communities of color (24). Mistrust stems from many sources, including sustained racial disparities in health care, limited health care access, lack of cultural competency among health care providers and researchers, and racism among physicians (25). Furthermore, patients of color have reported concern that their participation in research would not benefit their own communities (26). CBPR is designed to engage vulnerable populations in the research process to rebuild trust and encourage community ownership. Through shared resources, capacity building, shared decision making, and empowerment of community partners, not only the research outcomes and dissemination but also the CBPR process are intended to benefit research participants and their communities (27).

Some researchers and funders have suggested an ethical obligation to direct research toward reducing health disparities. Failing to understand the causes of health inequities, failing to use current knowledge to reduce health inequities, or supporting traditional power imbalances between the community and academia inhibit social justice and health equity (28). CBPR is an approach to addressing health disparities with equitable community and academic partnerships that promote an equal distribution of power between academia and the community.

Funding

As with other aspects of CBPR methods, obtaining research grants and determining project budgeting is a collaborative process. In the purest forms of CBPR, community partners are empowered, trained, and compensated appropriately for research and implementation efforts. Funding of community personnel and programs can help build community capacity (12).

Designing sustainable programs at the outset is imperative to ensuring continued community engagement beyond the grant period.

The National Institute on Minority Health and Health Disparities recently established a CBPR initiative to address diseases that disproportionately affect health disparity populations. Funding is directed toward community empowerment and developing sustainable programs that improve health behaviors and health outcomes. This initiative was launched in 2005 and since that time has funded 114 CBPR grants, including grants specific for CBPR planning and CBPR dissemination (29). Other funding agencies such as the W. K. Kellogg Foundation and the Patient-Centered Outcomes Research Institute (PCORI), a nonprofit nongovernmental organization, support research that uses a CBPR approach.

Challenges

CBPR can be a challenging time investment (13) for both academic researchers and community partners. Establishing effective, sustaining, respectful partnerships takes time and financial resources that are not traditionally a part of either an academic research team or a community organization's operations (30). Introductory CBPR activities include reconciling inherent cultural differences between academic and community partnerships, such as understanding the strengths and limitations of each collaborator, establishing expectations for grant funding, familiarizing community partners with research protocols, and resolving ethical considerations. This formative process of collaboration precedes the development of study design. This upfront investment in CBPR is not likely to yield traditional benchmarks of success for either academic partners (scientific manuscripts, grants) or community partners (community action, grants) but it will be valuable in the long term (31).

Because CBPR faces formative challenges, some of which may seem prohibitive to physician researchers, research methods that maximize as much community engagement as feasible may be considered an alternative approach. The concept of CBPR may be viewed on a continuum; at one end of the spectrum is

Table 2. Examples of CBPR initiatives targeting asthma

CBPR Initiative	Research Partners	Study Population	Innovation/Community and Health Outcomes
PESRAMHIP (34)	Brigham and Women's Hospital Two patient groups (one of African American individuals with asthma, the other of Latino individuals with asthma) Multiple representatives from community advocates for people with asthma	African American and Latino adults with asthma in Boston	Two groups of patients (one of African American patients with asthma, the other of Hispanic/Latino patients with asthma) have been contributing to study design, implementation, recruitment, analysis, and dissemination by taking part in regularly scheduled conference calls and in-person meetings. Patients will be randomized to routine care enhanced by asthma provider education vs. a novel asthma management strategy that includes use of inhaled corticosteroid at the same time as the use of a rescue β -agonist inhaler (a Patient Activated Reliever-Triggered Inhaled Corticosteroid [PARTICS] strategy). Funded by PCORI in 2016.
CHICAGO Trial (35)	Patient-centered outcomes researchers at multiple institutions including the University of Illinois at Chicago, Lurie Children's Hospital, Mount Sinai Hospital, University of Chicago Medicine, Cook County Hospital, Rush University Medical Center Patient caregiver and patient advocacy groups The Chicago Asthma Consortium Chicago Department of Public Health	African American or Hispanic/Latino pediatric patients with asthma in Chicago	Drawing on collaborations that span nearly 2 decades in efforts toward eliminating asthma disparities in Chicago, The CHICAGO investigators used qualitative interviews with caregivers, clinicians, and CHWs to design a clinical trial. The study is assessing the effectiveness of a provider-level intervention vs. an additional patient-level CHWs-led intervention that includes a focus on reducing environmental triggers at home. Study ongoing, funded by PCORI in 2013.
HEAL (40, 41)	Tulane University Schools of Medicine and Public Health Louisiana State University Health Sciences Center New Orleans Department of Health Multiple school districts including New Orleans Public Schools Daughters of Charity Services of New Orleans Multiple federally qualified community health centers	Pediatric patients with asthma in New Orleans in the aftermath of Hurricane Katrina	Determined that more than half of the studied children were living in homes that were damaged by rain or flooding. Environmental exposure reduction interventions were successful in improving asthma symptoms in the studied patients. Other HEAL initiatives promoted asthma awareness in communities. Led to a sustained educational program for asthma providers that has improved compliance with asthma management guidelines.
North Brooklyn Asthma and Environment Consortium (22, 42)	New York University El Puente: a community-based organization focusing on Latino health The Woodhull Medical and Mental Health Center A community advisory committee including local community leaders, neighborhood associations, and churches	Pediatric and adult patients with asthma in Williamsburg, a predominantly Latino neighborhood in Brooklyn	Survey questionnaires led to the implementation of culturally relevant asthma interventions, including inclusion of Latino folk medicinal practices. Enrolled hundreds of community members in an "asthma mastery" educational program Dissemination strategy included public art murals. Annual asthma-related hospitalizations in the studied community decreased from 1,166 to 484 over a 2-yr period Led to a 4-yr health promotion intervention funded by NIEHS

(Continued)

Table 2. (Continued)

CBPR Initiative	Research Partners	Study Population	Innovation/Community and Health Outcomes
The Healthy Public Housing Initiative (56–59)	Boston University Harvard University Tufts University multiple community-based organizations including: The Boston Housing Authority The Committee for Boston Public Housing The West Broadway and Franklin Hill Tenant Task Forces The Boston Public Health Commission	Pediatric patients with asthma living in public housing in Boston	Survey questionnaires and focus groups led to a home environmental intervention that improved asthma symptoms and quality of life for the 51 studied children (pre- and postintervention scoring using the Juniper Pediatric Asthma Quality of Life scale). Led to funding from the Kellogg Foundation to support resident education, public awareness, and systems change at the Boston Housing Authority, which ultimately led to a sustained community and university partnered program, the Healthy Pest Free Housing Initiative, that works to reduce environmental triggers in Boston public housing.
Boston Chinatown Asthma Studies (36, 43–45)	Tufts University Tufts New England Medical Center Chinese Progressive Association Josiah Quincy Elementary School South Cove Community Health Center	Pediatric Chinese immigrant patients with asthma in Boston	Survey questionnaires revealed unique issues facing Chinese immigrants regarding asthma control (e.g., difficulty translating key asthma concepts [wheeze] into Cantonese and limited asthma knowledge). Led to Blue Cross/Blue Shield Foundation of Massachusetts health disparities grant to develop and deliver a linguistically and culturally appropriate asthma education program in Boston Chinatown. This has now expanded into the APMI, which focuses on and prioritizes Asian-speaking families and features asthma prevention and treatment program components in the hospital, schools, and community. APMI currently serves >100 families per year through a home visit program, which includes environmental assessments, medication review, review of asthma action plans, and disease education for children and their families.
Community Action Against Asthma (46–51)	The University of Michigan multiple community-based organizations including: The Detroit Health Department The Detroit Hispanic Development Corporation The Arab American Community Center for Economic and Social Services Detroiters Working for Environmental Justice The Institute for Population Health	Pediatric patients with asthma in predominantly low-income African American and Hispanic neighborhoods in Detroit	Qualitative interviews and survey questionnaires led to a randomized clinical trial of 298 households and studied the effectiveness of CHWs (trained to improve the home environment and provide education). The intervention was effective in reducing indoor asthma triggers (dog dander and dust), improving lung function (measured by daily nadir FEV ₁ , and daily nadir peak flow), and reducing unscheduled health care visits for asthma over a 12-mo follow-up. Led to ongoing studies examining the impact of vehicle emissions and exposure to highways and the effects of household air filters on pediatric asthma outcomes in Detroit.

Definition of abbreviations: APMI = Asthma Prevention and Management Initiative; CBPR = community-based participatory research; CHICAGO = Coordinated Healthcare Interventions for Childhood Asthma Gaps in Outcomes; CHW = community health worker; HEAL = Head Off Environmental Asthma in Louisiana; NIEHS = National Institute of Environmental Health Science; PCORI = Patient-Centered Outcomes Research Institute; PESRAMHIP = Patient Empowered Strategy to Reduce Asthma Morbidity in Highly Impacted Populations.

traditional research (in which the study participants and community are minimally involved in the research process) and at the other end is CBPR. Viewing CBPR as a continuum may help researchers engage the studied community in some aspects of the research process, but it should be recognized that community engagement in other aspects of research might not be possible immediately and could be considered a long-term goal (32).

Addressing Pulmonary Health Disparities

Recently, the ATS made recommendations to reduce respiratory health inequities in the United States (33). Using CBPR to engage relevant communities and find collaborative solutions to improve pulmonary health outcomes for vulnerable populations is an approach to promoting respiratory health equity. To date, interventions to improve respiratory disease outcomes that incorporate CBPR approaches have been used primarily to address pediatric asthma (Table 2).

Recently, PCORI has funded several initiatives to address respiratory health equity. The Patient Empowered Strategy to Reduce Asthma Morbidity in Highly Impacted Populations is an ongoing randomized controlled trial that aims to determine if African American and Hispanic/Latino adult individuals with asthma will benefit from a patient-activated reliever-triggered inhaled corticosteroid strategy. Researchers at Brigham and Women's Hospital have partnered with African American and Hispanic/Latino patients to codevelop the study design, implementation, recruitment, analysis, and dissemination strategy. Other stakeholders engaged in the study include asthma advocacy groups, insurance agencies, and government officials (34). The CHICAGO trial (35), another PCORI-funded study that builds on multiple decades of collaboration among diverse stakeholders, is investigating the impact of multiple levels of provider and patient education on asthma outcomes in children of color presenting to emergency departments.

Another example is the Merck Childhood Asthma Network (MCAN), which has supported pediatric asthma

CBPR initiatives to improve asthma care, increase asthma knowledge, promote asthma-safe environments, and reduce childhood asthma disparities. Through adapting existing evidenced-based interventions and building community partnerships with school districts, city health departments, and community-based organizations, MCAN has implemented innovative pediatric asthma interventions in low socioeconomic and medically underserved communities throughout the United States.

Two formative examples of MCAN initiatives are the Inner City Asthma Study (ICAS) and the National Cooperative Inner City Asthma Study (NCICAS). ICAS and NCICAS were both randomized clinical trials supported by the National Institute of Allergy and Infectious Diseases, Physician Asthma Care Education (a physician asthma educational initiative designed to reduce the effects of asthma on children and their families) (36), and the Yes We Can Urban Asthma Partnership (a medical/social care model for outpatient, team-oriented pediatric asthma) (37). These clinical trials showed that interventions specific to a child's exposures and allergens were effective in reducing allergen levels and asthma symptoms (38, 39).

ICAS and NCICAS provided the evidence base for subsequent MCAN CBPR initiatives that recognized unique social and ecological environments to improve pediatric asthma in vulnerable populations across the country. One such example is Head Off Environmental Asthma in Louisiana (HEAL). HEAL was created in partnership with universities and multiple community organizations, including the Daughters of Charity Services of New Orleans and federally qualified community health centers, to focus on individualized environmental exposure reduction in pediatric patients with asthma in New Orleans in the aftermath of Hurricane Katrina. These interventions were successful in improving asthma symptoms in the studied populations (40) and improved compliance with asthma management guidelines (41).

HEAL initiatives also included promotion of asthma awareness in communities and led to a sustained educational program for asthma providers. The integration of research and

community-level action is evident from these initiatives. Researchers and community partners leveraged community resources to reduce environmental exposures that trigger asthma. Further research on these types of community interventions is imperative to demonstrate a return on investment and to facilitate more widespread implementation.

Other selected CBPR initiatives involve community partners throughout the research process to create culturally appropriate asthma exposure reduction interventions that could maintain a stronghold in the affected community (Table 2). The North Brooklyn Asthma and Environment Consortium (22, 42) reduced asthma hospitalizations through an asthma education initiative that incorporated local Latino cultural beliefs. The Healthy Public Housing Initiative partnered with the Boston Housing Authority to implement policy and sustainable programs to reduce exposure to asthma triggers in public housing units in Boston. The Boston Chinatown Asthma Studies (36, 43–45) developed asthma terminology that previously did not exist in Cantonese and improved communication with asthma-affected families. For almost 2 decades, Community Action Against Asthma (46–51) has led CBPR initiatives to enhance understanding of asthma in low-income neighborhoods in Detroit and has implemented programs that reduce indoor asthma triggers; it is currently investigating the effects of outdoor triggers such as vehicle emissions and exposure to highways.

To date, CBPR approaches to improving pediatric asthma outcomes have demonstrated promising results. However, few community interventions that incorporate CBPR approaches have addressed other populations or pulmonary diseases. The Saskatchewan First Nations Lung Health Project, an ongoing CBPR study of aboriginal people in Canada, is investigating how social health determinants at the individual level (such as health-harming behaviors) and at the community level (such as overcrowding and sociocultural factors including trauma related to colonization and racism) affect respiratory outcomes, including chronic bronchitis, chronic obstructive pulmonary disease, and obstructive sleep apnea, in addition to asthma (52).

Other examples include partnerships with a community health coalition targeting Chinese Americans (53) and with a public housing organization (54) that were leveraged successfully to promote smoking-cessation interventions. Another example includes a partnership between a university and an educational center serving foreign-born residents of Rochester, Minnesota, to improve tuberculosis screening, education, and testing among the center's students (55). Although these limited published CBPR efforts are promising, more pulmonary-related CBPR is needed, including CBPR focused on improving asthma outcomes in adults, in communities throughout the United States.

Conclusions

Despite advances in medical treatments for pulmonary diseases, substantial disparities in pulmonary health persist and are closely linked to populations of color and socioeconomic inequity. CBPR approaches that build on the expertise and resources of the communities affected by these disparities are needed to decrease disparities in pulmonary disease.

Application of CBPR principles, by incorporating some if not all of them, in pulmonary research is important to effectively engage affected populations of color and populations living in poverty, to

better understand the social determinants of health, and to develop better approaches to influencing those determinants of health. Use of CBPR principles is vital to translating medical knowledge into sustainable community-level action through empowerment and collaboration. However, further long-term research using the CBPR approach is needed among populations affected by pulmonary diseases beyond asthma, to provide additional evidence for a return on investment and to facilitate widespread implementation. ■

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