The West End Revitalization Association's Community-Owned and -Managed Research Model: Development, Implementation, and Action

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Abstract

Background: Principal investigators (PIs) of community-based projects are predominantly university faculty who partner with community-based organizations (CBOs) to find a place to conduct research in communities that will cooperate with their research objectives. University-managed research models (UMRMs) are not always beneficial for CBOs because the university usually manages the study, collects and owns the data, and leverages control at each stage of research, without priority to resolution of problems impacting the quality of life of participating communities.

Objectives: We present the principles of community-owned and -managed research (COMR), as a new community-driven research model developed by the West End Revitalization Association (WERA), a CBO in Mebane, North Carolina.

Methods: We describe WERA's development of COMR, compare the power hierarchies of COMR with traditional UMRMs, distinguish COMR partnerships from UMRM partnerships, discuss disbursement of funds, and control/ownership of data. As the PI of research activities, WERA drafted Memoranda of Agreement (MOAs) for all partners, including academic researchers, implemented quality assurance and control procedures, submitted community research protocols for institutional review, and retained data ownership for action, activism, and problem solving. COMR methods encouraged corrective action of environmental justice (EJ) problems in affected communities, including provision of public, regulated drinking water and sewer services.

Conclusions: COMR promotes CBOs with demonstrated organizational capacity to PI and project manager. The COMR model goes beyond UMRMs and CBPR because it emphasized the credibility and capacity of CBOs to develop, own, manage, foster, and sustain viable research agendas to address ongoing environmental hazards and related threats to health and quality of life.

Keywords

Environmental justice, community-owned and managed research, community-based participatory research, community-driven research, university-managed research model, basic amenities, drinking water, community development, research partnership

The shift to a community-based participatory (CBPR) research paradigm has been beneficial to many academic, government, and CBOs in addressing EJ and public health issues.[1–18] The CBPR approach (1) acknowledges the community as a unit of identity, (2) builds on community strengths and resources, (3) facilitates a collaborative, equitable partnership involving power sharing and empowerment process, (4) fosters co-learning and capacity building, (5) focuses on a balance between knowledge production and intervention, (6) focuses on locally relevant public health problems, (7) involves systems development using a cyclical and iterative process, (8) disseminates results to all partners and involves them in the wider dissemination of results, and (9) requires a long-term process committed to sustainability.[19,20] In many cases, CBPR has helped to (1) build trust, (2) overcome traditional barriers to partnerships and communication, (3) more effectively address health problems, (4) develop appropriate and more effective interventions, (5) create a better atmo-

sphere of collaboration, (6) cultivate a culture of "reciprocal benefits," and (7) utilize grassroots "know-how."[1–18]

However, PIs of CBPR projects are still predominantly university faculty. University faculty often partner with CBOs or health departments to identify willing and cooperative subjects for specific research goals and objectives.[21–26] Ideas that stimulate research questions are usually generated ahead of time by the university PIs and shared, to an extent, with community members after funding is acquired.[21–27] In practice, these university-managed partnerships are not always beneficial for community members seeking solutions because there is a different set of priorities/values for project management, data use and ownership, leveraging of funding for additional projects, tenure requirements, as well as control and authorization at each step of the research process (e.g., research question development; grant acquisition, data collection, storage, and analysis; and presentation/publication of the findings). Many CBOs with a high level of organizational capacity may benefit from a new, community-driven research model that addresses the imbalance of power and control inherent in UMRMs.

We highlight a set of COMR principles developed by the WERA, a CBO located in Mebane, North Carolina. WERA sought solutions-oriented research methods beyond CBPR and UMRMs to address the disproportionate burden of environmental contamination and hazards in three historically African-American neighborhoods. WERA developed principles and methods for community-driven research forged from its own set of tools and a priori knowledge of EJ issues, culture, and historical conditions in Mebane, North Carolina. This paper presents the theoretical basis and methods WERA and its partners used to develop and apply a research approach that stresses community creativity, ownership, management, and applied solutions at each stage of the research process.

BACKGROUND

History of the West End Revitalization Association

The WERA was founded in 1994 after a local newspaper published an article that mapped plans to construct the Highway 119 bypass through the West End community and up to the White Level community just outside the City of Mebane, North Carolina.[28–30] The bypass would be the northern connector through White Level for a new 27-mile, four-lane interstate from I-85/40 to Danville, Virginia. North Carolina Department of Transportation (NCDOT) studies revealed that 87% of the property lost to construction would be low-income African-American houses, churches, and a Masonic Temple in West End and White Level. The highway planning had taken place for over a decade without public hearings or input from homeowners suffering for decades without safe drinking water, failed on-site septic systems, dirt paths rather than streets, and a number of other environmental hazards that put the public at risk. Nevertheless, Mebane, Alamance County, and NCDOT officials had approved the plans and sought funding from the Federal Highway Administration.

In 1995, West End residents adopted bylaws and incorporated WERA as a 501(c)(3) tax-exempt organization. West End residents formed a board of directors of impacted residents, elected Omega Wilson as the founding board chairperson, and hired an executive director to handle daily operations.[31,32] WERA developed an organizational mission to improve the quality of life for low-income and minority residents denied basic amenities by (1) providing affordable housing, safe drinking water and sewer services, and voting rights, through economic, social, legislative, and legal means, and (2) empowering residents to address institutional racism that fosters racial inequities.[31,32]

Startup grant funding and technical training from the North Carolina Rural Economic Development Center in 1997 prepared WERA to become the only community development corporation in Alamance County. WERA's board reserved membership to representatives from regionally impacted African-American communities including White Level and Buckhorn/Perry Hill, which are adjacent to Mebane's city limits in Orange County. Over 500 homes, seven 100-year-old churches founded as early as 1868, and a Masonic Temple in these 85% to 95% African-American communities were threatened by new growth without inclusion.[28]

For 4 years, WERA conducted quarterly board and staff meetings; facilitated small-scale and community-wide strategy development and information-sharing meetings to address disparities in housing, infrastructure, and environmental hazards that threatened residents' public health; increased access to public records; and resolved blatant racial intimidation. In 1999, WERA and community residents filed administrative

complaints with the U.S. Department of Justice under Title VI of the 1964 Civil Rights Act and Environmental Justice Executive Order 12898 because of the disproportionate and adverse impact of plans for construction of the 119 bypass through West End and White Level.

WERA sought funding, problem-solving, and technical assistance to document EJ, public health, city planning, demographic, and geographic inequities by partnering with university researchers, elected officials, attorneys, and state associations. Local university researchers were selected because of their expertise and experience with planning and development issues in North Carolina. Researchers called on WERA and residents to (1) participate as a community partner on university-sponsored research grants; (2) give university researchers permission to conduct community-based studies in WERA communities; (3) transfer ownership of community data without crediting WERA or residents for data collection efforts; and (4) release the right to use and publish community data to support university-managed research centers without problem solving to mitigate environmental health hazards.[28–30] University PIs sought sole publication rights, the exclusive use of community data, and resisted participation in action-oriented problem solving with affected communities. Community residents expressed concerns about the ability of any UMRM to correct local EJ problems.

UMRM methods fell short of meeting residents' priority to obtain EJ and improve community public health, planning, and development.[28–40] Because of the issues mentioned, WERA terminated numerous university-managed research relationships with academic investigators, leading to the loss of grant funding.[35] Denying academic investigators access to communities and to community data was necessary because neighborhood residents entrusted WERA to protect their interests. UMRM relationships with researchers did not protect the historical integrity of WERA as an organization that had gained the trust and confidentiality of community residents.

WERA's need for an approach different from UMRMs grew out of residents' daily lived experience defending their right to obtain EJ by (1) organizing local EJ communities, (2) incorporating as a nonprofit organization, (3) developing a mission statement, (4) identifying local environmental hazards, and (5) mobilizing community support for corrective action of EJ issues. UMRMs were not responsive to WERA's unique and context-driven challenge to address local EJ issues. WERA and the communities it represents were in need of a collaborative approach that was more flexible and responsive to their needs and concerns.

In the next section, we contrast COMR with UMRMs, including CBPR, and present COMR as a viable alternate approach for community-driven, action-oriented research.

METHODOLOGIC APPROACH

Development of the COMR Model (How It Differs From CBPR)

The COMR model evolved from the lived experience of WERA members and neighborhood residents to address EJ and community planning and development inequities at the local level. The COMR model goes beyond traditional UMRMs, including CBPR, by emphasizing the credibility and capacity of the community to develop, manage, and sustain a research agenda and establishes that universities and other research institutions are not the sole purveyors of valid scientific research. Figure 1 displays an organizational schematic comparing WERA's experience with COMR to the power hierarchy of UMRMs. We use the term UMRM to refer to the way in which CBPR and other university-managed research partnerships are often developed, implemented, and sustained with CBOs. UMRMs, including clinical trials[41–43] and biomarker studies,[27,44–49] often incorporate community-based principles to increase participation of underrepresented, at-risk, or difficult-to-reach communities of color.[42,43,50–52] Affected residents rarely benefit beyond the term of the research study and their participation benefits the researcher and academic community by ensuring the successful completion of the study. Similarly, during studies that involve community advisory boards, university researchers often engage representatives from participating CBOs to narrow research questions and increase participation by subjects of color.[23,53–55] Yet, in CAB-engaged research, there are few long-term sustainable benefits after participation because community members have little assurance that the research partner will not pull out of the community when the study is completed or research funding runs out.[23,53–58] CBPR has led to more sustained long-term mutual benefits for community partners, but we suggest that CBPR does not go far enough.

COMR builds on CBPR principles by promoting collaboration with CBOs with demonstrated organizational capacity around defined EJ issues and the shift to a process where CBOs prioritize research goals. However, COMR differs from CBPR by requiring that the CBO be funded directly as the sole PI and project manager of research activities. This leads to more effective promotion of (1) the CBO's authority to select university "experts" whom they identify as amenable to their prioritized EJ or health issues, (2) community management of the research collaboration process to prioritize, maximize, and leverage available funding, and (3) community ownership of databases to ensure implementation of solutions for evolving community issues and corrective actions (after initial research and data generation activities are completed). In addition to the university institutional review board (IRB), WERA conducts quarterly board meetings, community-wide semiannual problem-solving progress reporting workshops with collaborative stakeholders (e.g., university researchers, attorneys, government officials, representatives from other CBOs and other technical advisors), and an annual dinner/workshop to review successes, failures, and new agendas. These differences provide the foundation for COMR to operate as an innovative model of community-driven research. COMR allows and encourages research and problem solving for a specific geographical area rather than aggregating results from multiple communities to observe trends. Use of aggregated community data to compare between or across case studies is more characteristic of university-led research.

Figure 1 shows a comparison of the involvement of affected residents and university investigators during the development, review, management, and sharing of information while conducting research in communities. Traditional academic researchers may be cautious of COMR methods because the process promotes a reversal of power in their relationships with CBOs and stresses commitment to long-term, sustainable, and community-owned and -managed problem

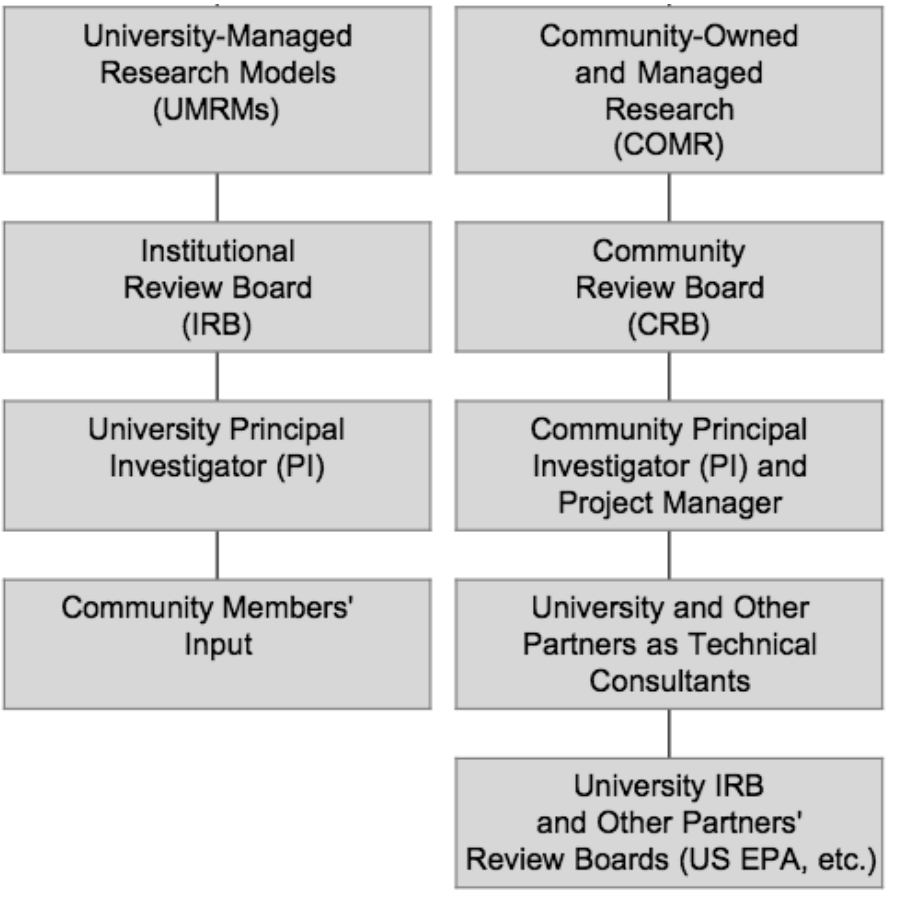

Figure 1. A Comparison of the Types of Research Approaches and Power Hierarchies

solving of EJ and health issues. As an example of the expression of power between partners, CBOs need university researchers to complete aspects of study design and data collection and analysis. But the CBO retains the power to hire and fire researchers and other partners based on the progression of the working relationship. University PIs more often invest energy and resources to collect data from communities to (1) document health problems, (2) compare differences in disease occurrence over time between exposed and unexposed groups, or (3) test the efficacy of short-term interventions to reduce harmful exposures, disease occurrence, or disparity between populations. These research activities tend to not effectively translate data into community solutions.[28,29] Short-term interventions are implemented in response to structural or community-level factors that are often already known by community members to be contributory factors to illness. CBPR does go farther by using participatory methods as a mechanism for capacity building, education, and empowerment; however, the CBPR model is not always applied and implemented by university researchers in a way that produces data to initiate compliance with and enforcement of existing civil rights, environmental, planning, and public health regulations. We demonstrate how COMR methods prioritize the community's goal for initiation of compliance and enforcement efforts by local, state, and federal government officials to address EJ, public health, planning, and civil rights violations of existing statutes and laws.

It is WERA's experience with UMRMs that led to the development of methods in which the community owns the data and manages the research process. COMR provides an alternate set of research methods that CBOs with a high level of organizational capacity can adopt to build and sustain action-oriented research agendas that prioritize the community's concerns and values at each stage of research.

Relationship With Communities

COMR is grounded in the principle that the community should be the center of knowledge production, project management decision making, data collection, learning, and social change rather than the university. COMR requires a high level of organizational capacity on the part of community residents to form a CBO, which should be an outgrowth of the EJ and health issues impacting the concerned citizens living in each of the affected neighborhoods. COMR may not be appropriate for all CBOs, especially those that are not well established or lack the personnel or infrastructure needed to support research. For example, WERA is a CBO with high organizational capacity that is staffed and operated by the members of the affected communities. In 1994, residents of West End, White Level, and Buckhorn/Perry Hill formed a board of directors and voted for a board chairperson and president of WERA. The board of directors, chairperson, and president drafted an organizational vision, mission statement, and bylaws, and mapped community historical boundaries that prioritized neighborhood EJ and infrastructure problems that needed to be addressed. Then in 1995, WERA incorporated as a tax exempt 501(c)(3) organization. This process ensured that WERA would be eligible to apply autonomously for funding opportunities while at the same time serving the interests of the community residents to solve local EJ issues.

After WERA established its organizational structure, it created training and mentoring programs for adult and youth residents, respectively. Training sessions for adult residents were designed to teach methods of systematic data collection such as survey distribution, environmental sampling, hazard identification, and community mapping. Trained residents were certified by WERA as community monitors and assumed more responsibilities during participant recruitment and data collection activities in the affected neighborhoods. This level of involvement by community monitors added assurance and trust in the research process by residents living in affected communities. This community-facilitated protocol allowed for confidentiality and double-blind data collection and database entry where university laboratories and supporting students/faculty were not aware of the identity of residents, water sample sites, or specific communities.

Local youth were mentored by WERA through a program called the DREAM Network. As community youth and young adults were exposed to the efforts of WERA, they began to request informed participation. To accommodate their interest, WERA planned the DREAM Network in 2000. Young residents learned about WERA's activities through PowerPoint presentations, digital photography of test sites, and trips to the University of North Carolina–Chapel Hill Laboratory of Environmental Virology and Microbiology (LEVM) and annual Minority Health Conferences. The DREAM Network

created opportunities for pipeline development so that youth from the affected communities could become educated and return home to contribute positively through economic development and revitalization efforts. For example, several youth entered the DREAM Network program as middle school students; after earning college and professional degrees, they returned to the affected communities to start childcare services and provide legal and administrative support for WERA activities.

Relationship With Academic Research Institutions

A major difference between COMR and traditional UMRMs, including CBPR, is that COMR promotes the CBO as the sole PI/project manager of research activities. CBPR and UMRMs often create a community project manager position or identify a CBO staff member to serve as a research project co-investigator. This methodologic difference between COMR and UMRMs is important because it allows the CBO to unilaterally or multilaterally prioritize research questions and study designs to meet the needs of affected community residents. The CBO collaborates closely with university and other researchers to develop study methods and research protocols; however, because the CBO is promoted to PI, it has the flexibility to change each step of the research process, including (1) the development and implementation of its own quality assurance and quality control procedures, (2) the submission of research protocols and materials for community review boards and other IRBs (e.g., universities, government agencies), (3) the planning of data collection efforts (e.g., household, environmental, and epidemiologic sampling and surveys), (4) the storage of address, contact information, household, and sampling data to protect participants' identity, (5) confidentially submitting data (e.g., survey results, photographs, testimony) to attorneys, the U.S. Environmental Protection Agency (EPA), the U.S. Department of Justice, and government agencies who leverage legal action and compliance, and (6) maintaining the sustainability of community-driven interventions.

COMR promotes the CBO's identification of collaborators that community members approve of and that the CBO is comfortable engaging with in collaborative partnerships. To facilitate this process, a standardized Memorandum of Agreement (MOA) is drafted by the CBO. For example, WERA created a standardized MOA to protect the rights and privacy of impacted WERA residents and property owners. WERA's MOA encouraged collaborators (paid or in kind) to select, based on their professional skills or expertise, from nine work groups. These nine work groups created teams that included university researchers, professionals, and other stakeholders who worked on strategic areas WERA had defined as important in its efforts to seek and implement corrective actions. MOAs clearly stated that the collaboration was not to support traditional, university-driven research and that all data collected during research activities would become the intellectual property of WERA. After collaborators completed signed MOAs, WERA worked with attorneys to develop contractual agreements to prevent conflicts of interest and to protect the rights of WERA and its individual members involved in research activities as community monitors and participants.

For all community–academic partnerships, the MOAs required university collaborators to propose a plan for research activities and served as a final step in selecting partners interested in collecting data to solve issues related to compliance and enforcement of violations of existing environmental and public health statutes in affected WERA communities (e.g., water collection to monitor compliance with the Safe Drinking Water Act and Clean Water Act). Compliance with and enforcement of existing environmental, public health, planning, and civil rights laws was the first priority of affected residents in Mebane, North Carolina, and through COMR methods, WERA had the authority to unilaterally direct research activities to initiate efforts supportive of their compliance and enforcement goals. At quarterly meetings of the board of directors, WERA reviewed and approved or terminated relationships with collaborators depending on the research activities they proposed in their MOA. WERA partnered with university collaborators who were willing to sign MOAs detailing the specific tasks they would be willing to complete and if they sought compensation for the completion of specific tasks. For instance, academic partners completed MOAs before they were able to assist in WERA training workshops for adult residents to become community monitors. After academic partners trained residents, they were compensated by WERA through a contractual agreement. This method of training community monitors to perform data collection activities double-blinded university collaborators.

The process of requiring MOAs for university collaborators reversed the power imbalance of traditional research relationships between CBOs and academic research institutions. MOAs help to ensure privacy of personal data and protect community residents who are harassed at their homes, in city council meetings, and other forums by local government officials. MOAs solidify the CBOs' role as the sole PI and manager of research activities, clearly outline its right to ownership of data, and ensure the prioritization of the concerns of affected residents throughout the research process.

Obtaining Research Funding for COMR

A central aim of WERA's COMR model is to expand the CBO's research infrastructure by pursuing an equitable share of grants that will in turn sustain the CBO's long-term strategic plan.[28,31,35,40,59,60] The EPA funded WERA as the PI and project manager of a community-driven research initiative through the Office of Environmental Justice Region 4 small grant and Collaborative Problem Solving Partnerships (CPS) federal research programs.[40] The EPA CPS grant process allowed WERA to incorporate COMR principles by requiring that the CBO serve as the sole PI and administrator of financial resources.[40,61] The CPS grant has helped WERA to solidify its COMR research infrastructure and implement actions to affect positive change in Mebane, North Carolina.[30,36,40] However, these grants are small in comparison to large research grants awarded to academic institutions as part of UMRM-related projects and centers. This disparity in funding institutionalizes the practice of academia studying communities without acting to resolve the problems and disenfranchises CBOs that seek research funding to support tangible, long-term, community-owned and -managed solutions.

APPLICATION OF COMR IN MEBANE, NORTH CAROLINA

In this section, we discuss how the application of the COMR model in Mebane, North Carolina, has helped WERA to successfully develop sustained relationships with local university researchers and laboratories and make progress to solve EJ-related problems.

Sustained Relationships With Local University Researchers

In response to these multiple problems, WERA partnered with informed university partners who adhered to COMR principles. In applying the COMR model, WERA has been able to sustain a collaborative relationship with the UNC School of Public Health (SPH) LEVM; graduate students and faculty helped to establish WERA's community water and sanitation training and surveillance program.[30,34,35–40,59,60,62–66] This program was implemented through an MOA between WERA and the LEVM who trained WERA's staff and community residents to develop and follow quality control and quality assurance procedures, become community monitors, distribute and collect household questionnaires, and collect water samples. While the community monitors identified survey respondents and sites for water sample collection, the SPH research team performed laboratory analyses to document fecal microbial contamination of community and private household drinking water supplies and recreational surface waters. Water sampling surveillance results documented noncompliance with the 1996 amendments to the Safe Drinking Water Act and the Clean Water Act. The SPH research team also trained WERA staff and community monitors to document household sanitation infrastructure and environmental hazards by collecting and analyzing household survey data.[28,29,31,34,35–40] This effort was more successfully led and managed by WERA staff who had recruited SPH faculty and graduate students to train community monitors. Faculty and graduate students, who were double-blinded during data collection, in turn relied on community monitors who were experts on their neighborhoods, local geography, and water resources.[28,29,31,34]

Progress to Solve EJ Problems

WERA's search for effective solutions to local EJ problems compelled it to apply a more flexible, community-tailored, and context-driven model compared with UMRMs. The diverse social, environmental, public health, economic, and political problems in WERA communities required flexible and context-driven methods to produce corrective actions of EJ issues. For instance, the City of Mebane had a long history of environmental racism and administrative and procedural inequity in the siting and/or regulation of environmental hazards in WERA neighborhoods; use of zoning, planning, and community development to redline WERA residents out of basic amenities and other services; and intimidation of disparately affected stakeholders by town officials.[40] WERA's "ground-truthing" using COMR methods led to a much more

productive and sustainable process for environmental health data collection to improve local EJ issues by initiating compliance and enforcement of existing environmental laws. WERA and its community monitors managed water sample collection and other surveillance activities in affected neighborhoods to document local and state government noncompliance with EPA statutes including the Clean Water Act, Safe Drinking Water Act, Clean Air Act, Solid Waste Disposal Act, and Toxic Substance Control Act.[28,29,31,34–40] WERA's COMR process of collecting environmental health data was effective in encouraging Mebane city officials to form taskforces with Alamance County and Orange County to provide matching funds for community development block grants for first-time municipal sewer and water installation and repairs to existing infrastructure in the affected communities.[28–30,34,59,60,63,64,66] It has also motivated corrective actions by the NCDOT to pave dirt roads, improve ditching for stormwater management, and substantially reduce the impact of the planned 119-bypass on West End residents.[28–30,34,59,60,63,64,66] Additionally, data collected by WERA on the quality of city, county, and private household drinking water supplies and recreational surface waters revealed that the water supplies contained levels of microbial contamination that exceeded EPA maximum contaminant limits.[28,34,59,60,63,64] WERA's COMR process of collecting "control" drinking and surface water samples at households with public, regulated water and sewer service revealed previously unreported violations of fecal coliforms in Mebane city water and the repeated failure of city officials to comply with public notice requirements to announce failures to water users or publish EPA-required public notices in area newspapers.[28–30,34,59,60,63,64,66]

CONCLUSIONS

There are many challenges when researchers and communities work together to form short-term or lasting collaborative research partnerships.[9,67] These challenges include creating and maintaining an environment of trust and respect, equitable sharing of power and financial resources, building mutually beneficial relationships, sustaining a focus on reflexive learning, and ensuring that environmental hazards that negatively impact health and devalue property are assessed, managed, and mitigated.[9,11,14,67–69] To create better health outcomes and sustainable programs, it is essential to have trained CBO boards, staff, and residents lead, own, and manage the research and intervention development processes.[4,70] By having more ownership over the process, CBOs can further empower vulnerable populations to manage the improvement of health and quality of life in their communities, whether it be (1) reduction of environmental exposures,[71–73] (2) promotion of better environmental health policies,[13,74,75] (4) improved asthma diagnosis and management,[76–78] (5) cessation of smoking among youth,[79] or (6) reduction of health disparities.[80–82]

We hope that environmental and public health researchers can benefit from a move away from traditional UMRMs toward the COMR approach. Local, state, and federal research funding initiatives exist that encourage researchers to contract their services to CBOs with a high level of organizational capacity. After failed attempts using traditional research methods, WERA's COMR model was the only approach that led to long-term, sustainable solutions to EJ and public health problems.

We have introduced the COMR model through a discussion of WERA's long-term strategic plan to address EJ issues in underserved African-American neighborhoods in Mebane, North Carolina.[28–40] We have highlighted the need for a change by academicians and researchers to support context-driven COMR methods that prioritize applied solutions to community-identified EJ problems in affected neighborhoods. In WERA's case, COMR helped researchers and the community to work more effectively to avoid the exploitation of affected residents while at the same time solving EJ problems. We acknowledge that similar results are achievable through CBPR methods[2,6,8,11,13,14,18,68,83]; however, we believe that the COMR methods developed by WERA provide a viable alternative approach to UMRMs and CBPR to achieve the EJ goals of marginalized communities. The development, application, and implementation of the COMR model in Mebane, North Carolina, has allowed WERA to develop strong coalitions with affected stakeholders and research advocates and positioned WERA to be a dynamic force for change of grassroots training, environmental planning, and public health policies both locally and nationally.

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