

2005

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Citation Details

Tumiel-Berhalter, L., Watkins, R., & Crespo, C. J. (2005). Community-Based Participatory Research: Defining Community Stakeholders. *Metropolitan Universities*, 16(1), 93-106.

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Community-Based Participatory Research: Defining Community Stakeholders

Laurene Tumiel-Berhalter, Robert Watkins, Carlos J. Crespo

Abstract

Community-based participatory research requires the participation of community stakeholders to inform the process. The West Side Community Asthma Project, a community-based participatory research program to study the effects of the environment on asthma conducted in Buffalo, N.Y., identified a stakeholders group of community leaders and activists. Creative strategies have been implemented to reach out to other community residents to invite them to participate in the participatory process.

Community-based participatory research has been defined as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings. Community-based participatory research begins with a research topic of importance to the community and has the aim of combining knowledge with action and achieving social change to improve health outcomes and eliminate health disparities.”(Community Health Scholars Program, 2004)

O’Fallon and Dearry (2002) offer six guiding principles for guiding community-based participatory research, particularly in the field of environmental health. These principles are endorsed by the National Institute of Environmental Health Sciences and indicate that community-based participatory research:

1. Promotes active collaboration and participation at every stage of research,
2. Fosters co-learning,
3. Ensures projects are community-driven,
4. Disseminates results in useful terms,
5. Ensures research and intervention strategies are culturally appropriate, and
6. Defines a community as a unit of identity.

Critical to the participatory process is clearly defining the community. Community-based participatory research involves activating the community to become part of the research process to study areas of concern that the community identifies. Researchers work collaboratively with a panel of community stakeholders to guide the design, implementation, and interpretation of the study. Through community involvement, research is made practical with the ability to translate findings into practice and ultimately make positive changes in the lives of the community residents. The translation of research findings into practice is critical to the improvement of health care delivery. For example, community-based participatory research has been noted an

essential component to enhancing the practical knowledge of family medicine that dictates quality of care (Stange, Miller and McWhinney, 2001).

Community Stakeholders

An essential component of community-based participatory research is community involvement at all stages of the process most commonly obtained through “stakeholders” groups. Ideally, the stakeholders group should be inclusive to best represent the defined community in which the research is taking place. Building and maintaining these groups requires clarity of mission and consistency in communication and involvement. Developing this relationship often requires a large time commitment at the beginning of the process but if nurtured will lay the foundation for a successful research program. Building trust and confidence in the process among researchers and the community is an ongoing process. Researchers cannot take for granted the responsibility of maintaining communication throughout the entire collaborative process.

Current literature describes stakeholders groups that guide the planning and interpretation of the research as including the academics, researchers, community-based organizations, and health department representatives (Eisinger and Senturia, 2001; Israel et al, 2001; Lantz, Viruell-Fuentes, Israel, Softley, and Guzman, 2001; Parker et al, 2003). Commonly missing from the list of identified stakeholders are community members who are not tied to an organization representing the unemployed or those working multiple jobs and taking care of families who do not have the time or the initiative to participate in community activities. Because of this, stakeholders may not be representative of the larger community and may not share the same opinions.

The West Side Community

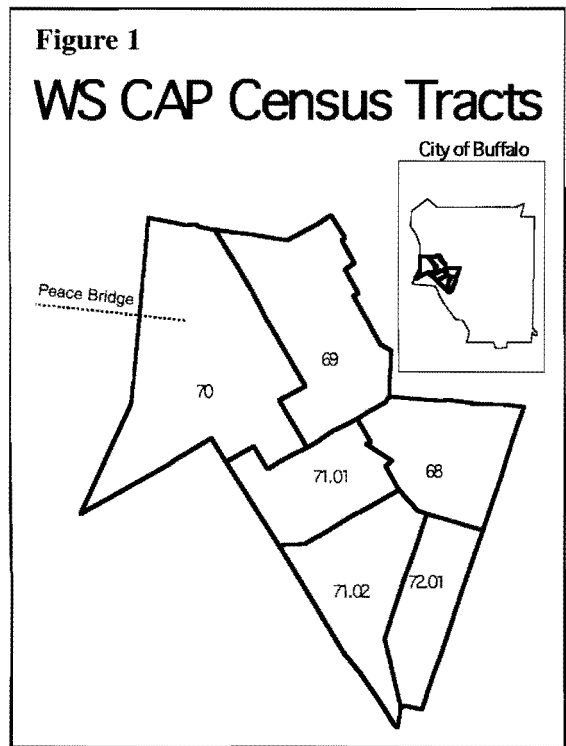
The purpose of this paper is to describe the challenges in identifying stakeholders that truly represent all voices of the community and to describe creative ways to encourage participation in the research process from the variety of individuals who define a community. There is a need to recognize various layers of the community and the many opinions that may exist within these layers. We offer recommendations to identify residents within various layers of the community and methods to better include the entire community in the participatory research process.

Community Characteristics

The West Side Community of Buffalo, N.Y., is geographically defined as six census tracts. Of these six tracts, three border on the Niagara River, separating the United States (Buffalo) from Fort Erie, Canada. These two cities are connected via the Peace Bridge, a major artery for U.S./Canadian commercial and non-commercial traffic. Built in 1927, the Peace Bridge now carries about 8 million vehicles a year (Buffalo and Fort Erie Public Bridge Authority, 2004). The Peace Bridge’s U.S. base lies in the heart of the West Side community. Figure 1 is a map of the area.

According to the United States Census (2000), the area is home to 24, 951 residents. Forty-six percent of those report their race as Caucasian, 25 percent as African-American; 35 percent report that they are of Hispanic origin, 86 percent of which are from Puerto Rico. The population is young: 27 percent under 18 years of age. Only 11 percent are over 65 years old. This is a poor community with 37 percent of households coming in under the poverty line. Twenty-two percent of households receive public assistance.

The population is faced with environmental and housing issues. Questions about the effect of diesel fuel emissions from the traffic on the Peace Bridge have been raised. Much of the housing is old and has been poorly maintained. Most of the residents are renters. Oftentimes these old houses present hazards that the resident can't fix or doesn't know about.



In 1994, a community health needs assessment was conducted by a family physician providing health care in a neighborhood facility. (Center for Urban Research in Primary Care, 1994) This is the most recent comprehensive health data we have for this community. Therefore, it serves as the baseline for many community initiatives. There were seven key findings made from this assessment:

1. Forty percent of Hispanic households reported problems understanding the language of the doctor and office staff.
2. Twenty-five percent of Hispanic adults had less than an eighth-grade education.
3. Forty-one percent of Hispanics reported their perceived health status as fair or poor, compared to 28 percent of African-Americans and 23 percent of non-Hispanic whites.
4. Fifteen percent of Hispanics, 14 percent of African-Americans and seven percent of non-Hispanic whites reported a doctor's diagnosis of asthma.
5. Twenty percent of Hispanic and African-American residents over 40 had a doctor's diagnosis of diabetes.
6. Fifty-two percent of male drinkers and 15 percent of female drinkers report risk of problem drinking using the CAGE questionnaire,
7. Forty-seven percent of men and 33 percent of women 18 years or older reported current cigarette smoking.

This process was participatory in nature. A group of community leaders and service providers were gathered together to inform the process. This group helped to develop the questionnaire. Community residents were hired and trained to conduct this door-to-door survey of 826 systematically sampled households that represented more than 2,000 people. The informant group was key to the interpretation of the data. They would react to the statistics putting the findings into context of what they were seeing in everyday life. Often, this resulted in restructuring the presentation of the data so that it made the most practical sense. This data quantified what the stakeholders already anecdotally knew. Now the community was empowered by real data to support its needs.

This was the beginning of participatory research in this community. This data was used for public policy and planning. For example, a new office structure was built in the community to provide a variety of health services to the community including a family practice office, a pediatric practice, and a dental practice. Mammography utilization data that was collected in the survey showed that women were not being screened according to recommended guidelines. This information was presented to the sponsoring hospital to identify the need since there was no place for women to go for the services in their community. In response, a mammography clinic was included in the plans for the new health center.

The success of this study led the way for other community initiatives to improve the health of the community.

Asthma in the West Side

In response to the high prevalence rates in the West Side, the Buffalo Asthma Study was conducted to understand asthma disparities in more depth. Households originally studied in the Lower West Side Health Needs Study were revisited. All self-reported asthmatics living in these homes were interviewed, along with a systematic sample of self-reported non-asthmatics. Both adult and child asthmatics were included in this study. In total, 167 self-reported asthmatics and 161 non-asthmatics were interviewed. Asthmatics were more likely to be Latino than African-American or white; more likely to receive public assistance and more likely to live in government-assisted housing. Forty-one percent of the self-reported asthmatics were defined as severe, 27 percent as moderate, and 32 percent as mild, according to the 1992 NIH classification. Environmental triggers, specifically mold, exposure to pets, and exposure to cockroaches were found to be associated with asthma (Kane, Jaen, Tumiel, Bearman, and O'Shea, 1999). This study showed that more than 90 percent of asthmatics did have a usual source of health care. However, asthma management was not up to par. Less than half of moderate and severe asthmatics reported being on an anti-inflammatory medication and, on average, asthmatics had five visits to the emergency room for asthma in their lifetime. Only half of asthmatics received any education about their asthma. Only one-third received an influenza vaccine in the last year and approximately one-tenth had ever received a pneumonia vaccine.

A qualitative component to this study indicated that the community associates itself with a lay model of asthma rather than the biomedical model. Specifically, the community recognizes asthma by symptoms, poor outcomes, and triggers but do not know or understand the medical definition (Zayas, Jaen, and Kane, 1999).

The West Side Community Asthma Project

The community was facing a larger challenge to their asthma problem. The current Peace Bridge was in need of repair. Many options circulated to address the need, many of which are politically charged. These included repairing the bridge, building a twin span, and building a brand new bridge in a new location. Recently, plans for construction of a new bridge have solidified in that the bridge will remain in its current location with the design to be selected. The more heated controversy stems from the discussion about the surrounding plaza that will be built to support the bridge and related traffic. These discussions have brought to light many issues regarding the effects on the community including community development, employment, housing, and health.

The community raised a concern about the high asthma rates in the community and how increased bridge capacity will affect asthma morbidity. Specifically, the community was concerned that exposure to diesel exhaust from idling truck engines and increased traffic on the expanded bridge will result in worse outcomes for residents with asthma. To confound the issue, the community also was concerned about the health effects of the construction process itself.

The process of expanding the bridge charged the community. Community residents demanded involvement in the process and appropriate considerations for all impacted areas of community life. Community leaders and the Peace Bridge Expansion Program responded by offering a series of town meetings for the community to voice their opinion. These were not often well attended. Tension built between the authorities and the community. The community felt as though the authorities were not doing enough to involve the residents and the authorities felt as if they were doing more than necessary but the community was not responding. In response, a community liaison was hired to be "on the streets" and bring information back to the authorities. Many committees have been formed to address specific areas of concern. Regular meetings continue to be held to stress community concern for the construction of the new bridge and corresponding plaza.

An environmental assessment is part of the planning process and is underway with results yet to be released. The gap in this assessment is that the findings will not be linked specifically to health outcomes. The community feels as though this linkage is important as any to make.

Community/University Partnership

In response to community concerns related to diesel fuel exposure and its effect on asthma, researchers from the university worked with community leaders as key informants to submit a grant in response to the Community-Based Participatory Research Program in Environmental Health sponsored by the National Institute of Environmental Health Sciences to develop a community-based participatory research program to gather community level data that could be used to inform the process. Key informants serving as representatives included health care providers, legislators, and individuals representing community-based organizations became part of the process.

This group provided input for the grant submission by providing their view of the asthma problem as well as the problems with the Peace Bridge construction and its process. They informed us of other groups that were conducting research in the community on similar topics. These individuals provided links with others who would potentially be interested in working with us on this project. We worked together to develop a template of a research plan that would be rewritten by the larger community. Written communication was maintained with all key informants as we awaited a funding decision.

The grant was awarded for five years and the West Side Community Asthma Project was born. The key informants were contacted again to initiate the process in the larger community. We requested their assistance in hiring a community coordinator. Critical to the success of the community-based participatory research efforts, the community coordinator needed to be from the community to understand the community and the challenges inherent in living there. It was also essential that the coordinator speak Spanish to communicate with the active Puerto Rican population in the community. The key informants spread news of the position within the community, reviewed resumes, and participated in the interview process. Many qualified candidates presented themselves. Making a decision proved challenging. With the help of the key informants a selection was made.

A bilingual bicultural coordinator was hired who lived and worked in the community for many years. She knew many of the key informants and was able to represent the project to the community. A name for the project was chosen with the help of the coordinator and the key informants. It was kept simple and, very purposefully, did not include the word research. We wanted the community to feel comfortable not threatened by the name. We also know that we could link community residents with other services.

The coordinator and key informants worked to define the mission of the West Side Community Asthma Project. We needed to clarify our role and position within the community so that expectations were understood and accepted. We needed to be explicit that we were not a service provider but could link residents with needed services.

The mission of the West Side Community Asthma Project is to:

- Build and maintain a partnership between community, university at Buffalo, and community-based organization.
- Enhance cultural competency of both the researchers and the community.
- Facilitate and increase awareness of different research and services being provided to the community.
- Serve as a source of information clearinghouse for the community.
- Conduct (stimulate) community-driven (initiated) applied research, services and education.
- Identify gaps in the research, services and education within the community.
- Empower the community to improve lifetime educational skills to improve health.

Initial Stakeholders

The first and perhaps most critical task of the community coordinator was to reach out to potential community stakeholders to inform them of our project and to determine their interest in participating as a stakeholder. Regular contact was required to maintain active interest among the stakeholders.

She began by revisiting key informants who helped guide the grant proposal and followed the leads that they provided her. Being from the community, she knew of other organizations and community groups that would be vested in the project. The university also linked the coordinator with other community groups interested in asthma and/or the environment. We linked with service providers who had forums available for contact with large groups within the community.

The response was overwhelmingly positive by all those contacted. The stakeholders recognized the asthma problem in the community and were concerned about the potential impacts from the expanded bridge. They were forthright and giving of their time. They, in turn, linked us with other organizations interested in the specific cause or those interested in the general health of the community. The project coordinator became involved in many community committees that allowed the West Side Community Asthma Project to participate in community programs such as health fairs and other celebrations. Through this participation, she was also to maintain regular links with community leaders and activists. This was critical to maintaining an active stakeholders group.

The breadth of the stakeholders group was impressively varied. Members included representatives from the local health maintenance organizations, the regional chapter of the American Lung Association, the Asthma Coalition of Western New York and the local health department. Large and small community-based organizations were represented. In addition, we recruited other university partners interested in environmental impact. Among these partners were representatives from the School of Engineering and the chemistry department. The University partners were essential in developing studies and approaches to our research that would allow us to make sound

inferences about the impact of diesel fuel exposure on asthma. Combining methodological techniques with the support and participation of the community would allow us to begin to obtain answers to the questions we were asking.

The West Side Community Asthma Project developed a formalized reporting mechanism to a community association that spearheads community activities and community politics, through their health subcommittee. This association played an active role in incorporating the community into the decision making process through the development of a Peace Bridge Committee. This committee was further broken down into subcommittees to deal with different community issues. Sub-committees include: housing, community development, and budget and finances. The West Side Community Asthma Project took the leadership role of the health and environment subcommittee. Since the efforts of this committee were parallel to the mission of the West Side Community Asthma Project, it made sense that the two merge. The data that we were setting out to gather would guide the process and inform the Peace Bridge authorities. It also allowed us a consistent reporting mechanism for our work.

Problem: The West Side Community Asthma Project began to hold stakeholders meetings in the evenings at a local community organization. Each meeting was attended by a handful of the stakeholders. Usually, different stakeholders appeared each time. We adjusted the time and day to accommodate and work around other meetings that were in conflict with the stakeholders meeting. Many other meetings were scheduled related to the Peace Bridge that were uncoordinated and often provided conflicting information. Our stakeholders attended many of these meetings as well. There were just too many meetings for the handful of individuals who attended.

The West Side Community Asthma Project team became increasingly aware of the uniformity of the stakeholders. The individuals who responded were the "meeting-goers" of the community. They were the employed, the educated, and the politically connected. These individuals brought many real and important issues to the table. However, they were busy and overcommitted so the consistency in attendance was low. These stakeholders truly feel committed to the issues and should be included in the process. We incorporate their input and follow-up on their ideas, appreciating the time they can give us. However, were their concerns and issues truly reflective of the community-at-large? We did not have the voice of the average community resident at the table. Diaz and Simmons (1999) would argue that this representation did not reflect a comprehensive participatory project.

The remaining challenge was how to reach other residents living in the community. Specifically, how would we reach individuals with socioeconomic barriers who do not have the time or initiative to attend meetings or those with family obligations that limit participation? How would we reach those who were not affected by asthma or had no interest in the Peace Bridge? How would we reach the illiterate, those who spoke only Spanish, or those that spoke neither Spanish nor English? We recognized that information from these groups was equally as important as that from the group of initial stakeholders. However, these groups would not be reached through traditional

meetings. We recognized that public meetings might not be the more culturally accepted mechanism for community members to address their concerns. Public meetings may also be logistically impossible for many people so much so that they are not even on the radar screen.

Solutions: In an attempt to truly make this project community-oriented, we developed strategies to gather input from the community-at-large. One project the West Side Community Asthma Project initiated was the development of an asthma registry. The team encouraged individuals who were asthmatic or who were the parent/guardian of a child with asthma to register. This was simply a mailing list of people that were interested in being contacted with asthma information or to be invited to participate in research studies. The registry was promoted at local events, health fairs and at the local shopping market. The registry was promoted at the local food bank and at senior citizens programs. The team also went door-to-door inquiring about asthma and inviting eligible families to enroll. Through this effort, we were able to identify those without asthma, those with asthma who did not want to participate, and those who spoke a language other than English or Spanish. By using multiple strategies to enroll families in the registry we were able to reach individuals who might not have had other opportunities to know about the West Side Community Asthma Project. Currently, there are more than 400 asthmatic families in the registry.

We decided to use this registry as a forum to gather opinions from the community about our research. First, community members were hired to help enroll families in the registry. These workers were trained in survey methodology and ethical issues in gathering confidential information. The workers informed us what worked, what didn't, what people said, and what they wanted to know. The workers live in the community and are regularly communicating with other residents. They know what problems are being faced in the community and how we can best reach people.

We used different research methodologies to connect with families in the registry to incorporate them into the participatory process. We developed short surveys that ask about concerns related to the Peace Bridge. Due to the challenges in reaching under-served populations, we developed a multi-method strategy for contacting hard-to-reach families. Contact was first tried by telephone, then by mail. If contact still hasn't been made, a community worker drops by their home. Surveys have also been distributed in other group forums. Preliminary findings suggest that one-third of the respondents were concerned about the health effects of the bridge expansion and one-fourth were concerned about the impact on their housing.

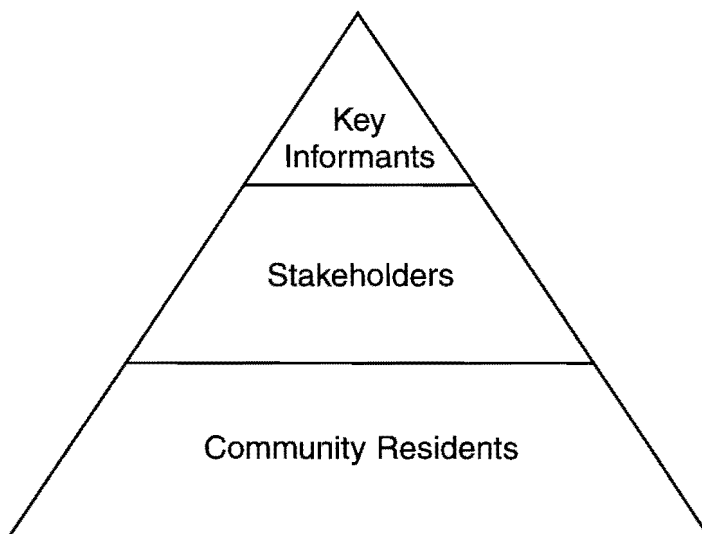
We are also planning to use focus group methodology as a mechanism for gathering community input to guide our research. The groups will be held locally. Dinner and childcare will be provided for participating families. We feel it is important to make it a family event to make it more accessible. The purpose of the first focus group planned is to identify the community's perception of air pollution and health. Other such groups will be formed as topics of interest arise.

Lessons Learned

Many lessons have been learned from our process of incorporating the community into our research. The most important and overarching is to never stop learning from the community. The process requires acute observation and creativity to address holes in our scientific techniques. We learn many things by just being present in the community and listening to people's stories. The stories provide a framework and a cultural context for us. These stories are earned through consistency and trustworthiness. Bumps in the road are to be expected but we must learn from them and encourage community participants to also learn from them. We need to encourage the community to learn more about the research process and us. Oftentimes, communities do not understand some of the restrictions and bureaucracy we must adhere to by being part of the university. An understanding of one another's culture is core to the learning process.

More specifically, we need to spend the time to clearly define the community of interest and more importantly to gather information and ideas from the various layers of community residents. It is critical to know your target population and whom the results of your study are affecting in building your stakeholders group. As Figure 2 depicts, community residents are the foundation of the participatory process. By including only key informants and traditional stakeholders, we are neglecting the people most need of health improvements identified through our research. We must also be cognizant that within each global layer are community groups that are unique and independent and may require different strategies for inclusion into the participatory process. The community layers are dynamic. The people may change and their needs may change. Participatory research suggests long-term relationships that recognize and survive these changes.

Figure 2. Layers of the Community



We need to go to the community and not expect the community to come to us. Traditionally, we have expected community residents to answer our general call for participation in research. This has only reinforced the “guinea pig: approach to research. We need to be visible in the local grocery stores, the food banks, and other community gathering places to personally invite participation. Our approach toward the invitation is critical to reaching the various layers of the community. This also holds true with the various sects within each layer.

We need to take the time to educate the community on the issues and determine if it is important for them. The community may not be aware of the issues that we the researchers hold dear to our hearts. The issues of the stakeholders and key informants may not be the same for some of the community residents. We need to really listen to what the community is telling us and be able to differentiate the issues between the layers to determine what the true issues are. Concerns at all levels are important but may be different.

No one’s time is free. We need to “give” the community something in return for its time. This could be in the form of incentives, flow of information back to them, or simply respect for their time and situations. Appreciation is mutual. Researchers must take the time to identify what reimbursement is meaningful to the various layers of the community.

Researchers committed to conducting community-based participatory research must be open to creative, non-traditional ways to reach certain members of the community. We can use a combination of techniques to be inclusive of the variety of individuals we are trying to reach. Figure 3 summarizes some methods we have used to reach out to the community. One of the challenges in using this approach to research is the uncertainty of how things will play out. The control of experimental design is replaced with ambiguity of translating that research, wondering if the population you are trying to serve will embrace interventions or approaches. Even though the outcomes may be “soft,” these approaches will guide our more scientific methodology providing the richness of a cultural context. These methods will help us to empathize with the community we are working with to understand their plight. We can use this information to develop impact and outcome measures that are meaningful in practice.

These outcome measures may be non-traditional but may have more of an affect on quality of life than the traditional measures that so restrict us.

| Figure 3. Methods for Gathering Community Input |
|--|
| In-Depth Interviews |
| General Meetings |
| Focus Groups |
| Opinion Polls |

We must be visible to the community and clearly working for them and with them. This is often challenging due to tight work schedules. Even though the community liaison is the main community presence, it is critical that the researchers are hands on and recognizable to community members.

We must also take the time to explain the culture of research and academia to the community. We must describe how our level of precision and adherence to policy can work for the community by providing the sound evidence to support their often-anecdotal requests for services or demands for attention. We need to share the data we collect and show how that data can be used to bring funds into underserved communities. We can work with our partners to expand access to already existing services.

Conclusions

Community-based research is fulfilling to researchers and tremendously critical to translating research into practice. It deserves the time spent to determine if your stakeholders group is representative of your target population. Reaching out only builds trust and appreciation for one another's culture.

We have learned through our efforts and those of others documented in the literature that the participatory process is far from perfect. We are asking the community for a huge commitment by being involved at all levels of the process. This may be too large of a commitment for some. Dynamic community involvement should be expected and does not diminish the impact of participatory findings (Diaz and Simmons, 1999). It is our job as researchers to be inclusive of the community as projects evolve.

Stakeholders are an essential component of conducting community-based participatory research. A community cannot be observed as uni-dimensional but rather a complex dynamic entity. We cannot underestimate the power of the non-vocal community. These are the individuals who may be in the most need. Researchers need to work out of the box to ensure that their findings are representative of the whole community and should never assume that all factions of the community are represented. To remain true to the paradigm of community-based participatory research means to always be open to new people and new ideas.

Acknowledgements

We would like to acknowledge the National Institute of Environmental Health Sciences for funding the West Side Community Asthma Project. We owe our utmost thanks to Victoria McLaughlin, the West Side Community Asthma Project coordinator, for leading outreach efforts and the residents of the West Side community of Buffalo, N.Y., for their continued support and participation.

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