
Community Involvement in the Conduct of a Health Education Intervention and Research Project: Community Action Against Asthma

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There is a need for more guidance on how to implement community-based participatory research, particularly on the roles of community members, throughout the process. This article focuses on how a Steering Committee, composed of representatives from community-based organizations, a local health department, an integrated health care system, and academia from the University of Michigan, participated in the design and implementation of a children's asthma study in Detroit, Michigan: Community Action Against Asthma. In addition, this article focuses on the role of community members as data collectors, examining a variety of sophisticated data collection roles. A description and analysis of how community members shaped and participated in the project, the lessons learned, and recommendations for practitioners are also presented.

Keywords: *community-based participatory research; health intervention; asthma; community involvement; collaborative research; partnership; data collection*

Although there is growing recognition of the benefits of community-based participatory research (CBPR) (Green & Mercer, 2001; Israel et al., 2003; Parker et al., 2003), there is little in the published literature about how CBPR methods have been used in the day-to-day conduct of health education research interventions and traditional epidemiological studies. Much of what is written focuses on the process of forming the initial participatory collaborative, rather than on how

the research and intervention are implemented using a partnership approach. There is a need to address questions such as How do you continually involve community members in participatory research? What are the processes to encourage community participation in the decision making and conduct of the research? How can you involve lay community members in data collection, and what tools and supports are needed?

In this article, we focus on how a Steering Committee, composed of community members and representatives from community-based organizations, a local health department, an integrated care system, and academia actively participated in the design and implementation of a CBPR epidemiological and health education intervention study. The study seeks to increase our understanding and address environmental triggers of

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childhood asthma. In addition to involvement as Steering Committee members, community members served in key data collection roles. We describe and analyze: how community members shaped and participated in recruitment, incentive selection, development of retention strategies, and the collection of questionnaire, air sampling, and lung function data. We also describe lessons learned and recommendations for practitioners.

► BACKGROUND AND LITERATURE REVIEW

History

There have been increasing calls for more CBPR in public health (Green & Mercer, 2001; Israel, Schulz, Parker, & Becker, 1998; Northridge et al., 2000; Olden, Guthrie, & Newton, 2001). CBPR has been defined as a collaborative research approach equitably involving all partners in the understanding of a given phenomenon, and the translation of the knowledge gained into policies and interventions that improve the health and quality of life of community members (Israel et al., 1998). CBPR emphasizes the value and necessity of involving the community as full partners to enhance the quality and relevance of the data; overcome the understandable mistrust of research that exists within many communities of color and keep public health and health care focused on real community needs (Black, 2000).

Community Action Against Asthma (CAAA) grew out of an already existing CBPR partnership, the Detroit Community-Academic Urban Research Center (URC) (Israel et al., 2001). In response to the URC identifying illnesses related to the environment, such as asthma, as a priority area to focus on, the URC submitted a request to the U.S. Environmental Protection Agency and the National Institute of Environmental Health Sciences for the Michigan Center for the Environment and Children's Health (MCECH). The CAAA project of MCECH combines an epidemiological study of environmental asthma triggers for children with asthma with an intervention study to reduce indoor environmental triggers for children with asthma.

What Is CAAA?

CAAA's aims are to (a) implement a household health education intervention to reduce indoor triggers of childhood asthma and (b) assess indoor and outdoor air quality effects on exacerbation of asthma in children. The health education component involves a household intervention consisting of a minimum of 12 visits over a 2-year period by community environmental specialists (CESs), who are community outreach workers. CESs provide education about asthma, work with the family to develop an individual plan to reduce asthma triggers, make referrals, and provide materials necessary to alter the home environment. Evaluation of the household-level intervention used data from the

epidemiological study as well as an annual household walk-through, and caregiver and child questionnaires that assess psychosocial stressors and protective factors, behaviors, environmental triggers in the homes, and health status. The epidemiological study collected data on ambient outdoor and indoor environmental exposure and the health status (e.g., lung function, asthma symptoms) of the children who enrolled in the project ($N = 331$).

A Description of the Communities Involved

CAAA was conducted in neighborhoods on the east and southwest sides of Detroit, Michigan. Among the caregivers enrolled in CAAA, the eastside is predominantly African American, and the southwest side is the area of the city in which the largest percentage of Hispanics reside. Of these caregivers, 78% have annual incomes of U.S.\$20,000 or less, and 46% have annual incomes of U.S.\$10,000 or less. The average family size is 4.99, and 70.53% of adult caregivers have a high school or GED education or less. Participants in the project were recruited through an epidemiological screening questionnaire mailed to caregivers of children age 6 to 10 years enrolled in Detroit Public Schools in the two communities involved. If, based on the caregivers' responses, their children were identified as having probable or known persistent asthma, they were invited to participate in the study.

The Role of Community Partners

CAAA is guided by a Steering Committee composed of representatives of the University of Michigan, the Detroit Health Department, a health care system, and community-based organizations and agencies chosen for their involvement in the community and their interest/expertise in environmental health. Steering Committee representatives are from many of the same partner organizations involved in the URC (see Authors' Note) and come from community-based organizations ranging from small staffs of five with a limited budget to large, multipurpose agencies; they focus on issues ranging from health to housing to the environment and are all well respected and embedded in the community. (For a further discussion, see Israel et al., 2003.) The Steering Committee adopted a set of CBPR principles originally approved by the URC Board (Israel et al., 2001) emphasizing involving the community in all major phases of the project, working to strengthen collaboration and enhance the capacity of all partners, conducting research that is beneficial to the community, and disseminating findings in ways that are understandable and useful. The Steering Committee meets monthly at alternating partner organization sites and, in keeping with the CBPR principles, was integral to every aspect of the work of the project. For example, the Steering Committee participated in the original project design and the design of all survey instruments. It has

been involved in all major decisions of CAAA, including hiring of personnel and helping establish two field offices in Detroit. Community partners ensure that CAAA provides a community service and that all activities are undertaken in ways that are culturally appropriate, responsive, and sensitive to community needs (Parker et al., 2003).

The CAAA intervention used a staggered intervention design in which households were randomly assigned to one of two waves. Wave 1 households received an intensive household intervention averaging nine visits the 1st year and three support visits the 2nd year. Wave 2 households began the same intervention 1 year after the Wave 1 families, thus initially serving as a control group and subsequently receiving the intervention. The main study comparison was for Year 1 between Wave 1 and Wave 2. Originally, 331 households were enrolled, and a total of 302 were still in the study 6 months later at the time the intervention began.

► METHOD

The description and analysis of the role of the Steering Committee and the community members presented in this article comes from minutes of meetings and training sessions, documentation records, and interviews with the CESs and Steering Committee members (Parker et al., 2003). The interview data were analyzed using a process of focused coding and the constant comparison method (Glaser & Strauss, 1967; Parker et al., 2003).

The Role of the Steering Committee and Community Staff in Recruitment

The Steering Committee elected to recruit participants through the schools, rather than established medical facilities, to ensure the possibility of identification and recruitment of previously undiagnosed children with asthma. It also helped draft a recruitment brochure in a question-and-answer format that included a map of the study area and a specific list of schools to be involved. In addition, the Steering Committee reviewed the initial screening questionnaire developed by the faculty researchers at the University of Michigan and suggested changes based on cultural and literacy issues. For example, the categories used to identify ethnicity were changed to better reflect words actually used in the community. These activities are in keeping with the CBPR principles of involving community partners as active participants in all major phases and in producing information for the community in clear, respectful language (Israel et al., 2003).

Project plans originally called for screening questionnaire distribution to be carried out directly through the schools where children would be instructed to take the questionnaire home for their caregiver to complete. Instead, because of some situational factors, school officials agreed to facilitate the mailing of the question-

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naires to all students meeting the eligibility criteria (i.e., age, location). Steering Committee members expressed concern about the likelihood of achieving good response rates and directed university-based staff to research direct mail campaigns. When the staff shared a classic article on increasing response rates for mailed surveys (Dillman, 1991), the Steering Committee noted that the recommendations might not be appropriate in the context of Detroit, particularly in the area of incentives. To address this concern, it asked for a pilot study to be conducted to test the effectiveness of different incentives. Using two schools, families were divided into incentive groups, those who received (a) a \$2 bill, (b) a \$2 gift certificate to a local shoe store, (c) a \$4 gift certificate to the shoe store if they brought their completed survey to one of four community partner agencies, or (d) a \$4 gift certificate to the shoe store only after mailing the survey back. The shoe store gift certificates were chosen because of the easy accessibility of these stores in the Detroit area and their willingness to provide a discount. The results of the pilot test showed that, with the exception of the third option, there was no difference in response rates. Therefore, the Steering Committee chose the option cheapest and easiest to administer: option d.

The recruitment coordinator (who later became the field supervisor) and the CESs were all hired from the community. Job announcements were posted in community partner agencies, and an advertisement was placed in a small local newspaper. Two of the CESs had prior experience working as outreach workers.

Although the third CES did not have such experience, members of the Steering Committee who participated in the hiring process felt strongly that given her other strengths (e.g., bicultural, bilingual) hiring her would also serve to enhance community capacity, a key principle of CBPR. The recruitment coordinator and CESs were interviewed and hired by a group composed of Steering Committee members and university-based staff, consistent with the CBPR principle of involving everyone in major project phases (Israel et al., 2003).

The Role of the Steering Committee and Community Staff in Data Collection in the Field

All the CAAA data were collected by trained lay community members who, prior to their involvement in CAAA, had little or no experience in data collection. During the first 3 years of the project, 105 different people, 96 of them Detroit residents, were paid by the project to conduct various aspects of the project's work. Although studies exist in which lay community members have been involved in social-science questionnaire data collection activities (Schulz et al., 1998), we did not find examples of research studies in which lay community members collected technical and mechanical data, such as air-monitoring and lung-function data, independently as they have in CAAA. We describe the different data collection roles of community members in the order in which they took place.

The allergy skin-testing fair. For the intervention and epidemiological exposure assessment components of the study, it was necessary to identify children's sensitization to commonly known environmental allergens, including cockroach, dog, cat, rat, mouse, ragweed, grasses, and alternaria. To accomplish this, the Steering Committee decided to hold community-based skin-testing fairs so that participants could bring their child to a familiar site for the procedure.

Before the Steering Committee would approve skin-prick testing, they met with the allergist in charge and were informed of the standard procedure for tests to be given on a child's back, partly so the child would not be frightened by the sight of the needle. The Steering Committee decided to have the tests administered on the forearm instead, reflecting a concern that caregivers might be reluctant to have a child remove his or her shirt in a situation where there was little privacy. We sent an appointment reminder letter with answers to Questions Caregivers Ask, developed in consultation with community partners who could anticipate some of the caregivers' possible concerns. University of Michigan staff, volunteer graduate students, health professionals, and community members helped staff the fairs. Spanish-speaking staff were present at all fairs where Spanish-only families were expected to attend. Based on community partners' input, the fairs were held at partner organizations on the east and southwest sides of

the city, transportation was provided, and activities for siblings were also provided.

Collecting annual survey information using community interviewers. The annual data collection activities conducted for the project included a caregiver questionnaire, a household walk-through—assessing a variety of household characteristics, the collection of a sample of dust in the child's bedroom, and a child's questionnaire. The dust collection component is especially unusual for a lay community person to carry out per our review of the literature, in that university researchers are usually responsible for any dust collection in a research study (T. Dvonch, personal communication, 2002).

Community interviewers. The Steering Committee decided that community members should be hired and trained as interviewers, noting that they would be more effective in establishing rapport gaining access to homes than would university students or professional interviewers. Forty-one community members received training and carried out interviews as part of CAAA, and many of them subsequently found interviewing jobs with other university-affiliated projects. In this way, community members gained a transferable skill that expanded their job opportunities and enhanced community capacity.

Recruitment of interviewers. To recruit interviewers, we posted fliers with job duties, qualifications, and our toll-free number at community centers and churches and handed them out at community meetings. We held a screening session at a community partner's office where staff explained the job's challenges and screened applicants on literacy levels, past work experience, and interpersonal skills, sometimes soliciting second opinions or checking references. Of those who attended the screening, 90% were invited to attend the training.

Training of interviewers. Interviewer training took place over a Saturday and three evenings so as not to interfere with interviewers' regular jobs, for a total of 16 hours. Project staff, with community partner input, adapted trainer and trainee's manuals originally developed by the East Side Village Health Worker Partnership (Schulz et al., 1998). Training included role-plays and hands-on experiences. Interviewers also learned about study protocols for conducting the household walk-through and practiced collecting household dust samples. Experienced interviewers were utilized in subsequent training sessions to model and present their knowledge and experience to their peers and role-play typical interview scenarios. To enhance the evaluation of potential interviewers, we added a mock household walk-through and mock interview with a trainer who evaluated them based on their performance, and all but five of those who began training were selected.

Conducting the interviews. Interviewing began immediately after training. The Steering Committee chose an incentive of \$15 for a completed interview, and the interviewers suggested also providing a small gift for the caregiver (such as a picture frame or pot holders) and coloring books and crayons for children in the household. The Steering Committee asked that the financial incentives be mailed to the caregiver on completion of the interview to avoid having the interviewers' safety threatened by carrying cash. All completed interviews were turned in to the project's field office and checked for completeness and accuracy, and new interview materials were distributed.

Collecting data from indoor air-sampling machines and personal monitors using lay community members: The role of air-sampling technicians. The CESs also served as air-sampling technicians during the "seasonal intensives," which were 2-week intensive data collection periods each season for a total of 11 seasons over 3 years. They collected data using the indoor air-sampling (IAS) machines and personal monitoring machines. Each CES went into the homes of two to four clients, sometimes as early as 6:30 a.m., to change filters on the IAS machines, to change batteries on the personal monitoring devices placed in the backpacks worn by the children, and to ensure that the machines were working properly.

The air-sampling duties the CESs performed are technical and are rarely performed by laypersons acting without support. The CESs participated in 10 hours of training in the laboratory and an additional 16 hours of training in the field to ensure they had the skills and knowledge to undertake these duties.

One of the challenges of this component was recruiting project families to participate. Families in this component would have their child wear a backpack with the personal monitor each day when away from the home and have an IAS machine in their homes. The IAS machines are 24" wide × 23" tall × 15" deep, have filter sample inlets above the IAS pump box making the box and outlet 4 ft above the floor, and hum continuously when plugged in. Originally, university researchers planned to have the project manager call families to secure their participation. Community partners expressed skepticism that anyone would agree to participate and felt that it would be unfair to ask anyone to agree without seeing the machines. A community partner experienced in making home visits in Detroit volunteered to visit selected homes, with photographs of the machine and the backpack, to obtain family approval. In addition, substantial incentives were offered, such as a \$20 check for additional electricity used, a personalized gift for the caregiver, and a \$35 gift certificate to a local restaurant for the entire family for each season. This approach was successful with 20 of 21 families who agreed to participate.

The CESs often comment on the need to be resourceful, easygoing, and nonjudgmental to ensure the quality

and continuation of the data collected. One CES, recognizing the need to help a busy mom get her kids off to school while collecting data, described turning the breakfast bacon while a caregiver attended to other matters. Another told of being invited to eat breakfast each morning by one client, an unexpected pleasure of the job. All told of the IAS machine's use as a space to place clothing and household items because it took up needed space, and of the challenges to accurate data collection of curious, playful children tinkering with the machine.

Collecting data on lung-functioning and daily asthma symptoms and health status using community workers. Correct technique and consistent use of the Airwatch lung-function monitor (www.IMetrikus.com) and the completion of the symptom, medication, and activity-level daily diary were essential to obtaining accurate data. We recruited community "Airwatch distributors" to be trained on the use of these data collection tools in much the same way as interviewers. In addition, many of the interviewers took on this role as a new job. The job of the Airwatch distributor was to go into the homes of project families each season to deliver the Airwatches and diaries and train and retrain the family on correct usage.

The Airwatch distributors provided feedback to the caregiver and child about their Airwatch monitor performance by showing them a graph from the previous season that depicted their child's lung functioning and showed if the child had been using the monitor as directed. In those instances where the graph showed incorrect technique, the distributor provided additional education and support to the child. Originally, we attempted to reach all 302 children each season to collect these data. After the first five data collection periods, the protocol was changed to allow for at least one observed blowing period a day resulting in a smaller subset of 62 children using the Airwatch each season, with the remaining completing only the diary. The children from these 62 families were observed each morning at school by one of nine Airwatch coaches during the final six seasonal intensives. We recruited community members with medical skills by contacting local hospitals as well as respiratory therapy training schools and successfully recruited six Airwatch coaches with some previous medical experience.

Retention of Project Participants

Retention in a longitudinal research project is always a challenge, and maybe even more so in a low-income, urban population where community members face multiple life stressors making participation an added burden. Steering Committee members and community staff warned us that the high mobility of some people in Detroit, along with sizable numbers without continuous telephone service, would make ongoing communication with research participants challenging. For a pro-

ject such as CAAA, an additional retention concern was the multiple demands asked of participants. The Steering Committee members and community staff were very involved in developing retention strategies. Nearly 78% of participants remained with the project at 1st-year follow-up data collection. We think the relatively high retention rate among those participating at the start of the project is because of a combination of factors, including the incentives discussed later. We also believe that community staff were better able to establish relationships with the families than professional staff, thus contributing to this retention rate. We widely publicized our toll-free number so if a participant changed an address or phone number, had a question, or wanted to contact a CES worker, she or he could do so easily. We also had frequent communication with families through face-to-face or telephone contact by the interviewers, CES workers, and Airwatch and diary distributors and through postcards every season, holiday cards, birthday cards, and newsletters with coloring contests and raffles (suggested by community partners and staff). Finally, appreciation events were held, such as a field trip to the University of Michigan for the indoor air-sampling families who toured the lab where dust filters were analyzed, and a thank-you party at the end of the 1st year attended by more than 200. The idea for the party came from the CESs and the field supervisor, and they planned and carried it out.

The Role of Incentives

The Steering Committee and community staff were instrumental in designating appropriate incentives. As part of the intervention, CAAA provided vacuum cleaners with high efficiency particulate arrestor (HEPA) filters; bedding covers for the child's mattress, box springs, and pillows; cleaning supplies (e.g., bucket, mop, sponge, soap, all of which were bought at local dollar stores to ensure easier replacement by the families after the project ended); and integrated pest management. In addition to these items, direct incentives were given to participants, such as \$15 gift certificates to a multipurpose store after the completion of each lengthy interview; toys at the end of the week for the children who used the Airwatch in school; and gift certificates to a local restaurant for a successful record of Airwatch blows. At the project's end, each family remaining with the project received \$50 as a token of appreciation.

► DISCUSSION AND RECOMMENDATIONS TO RESEARCHERS AND PRACTITIONERS

In CAAA, we learned a number of lessons using a CBPR approach that have implications for those undertaking research, and for practitioners implementing and evaluating health education interventions.

Set Up a Systematic Process for Ongoing Feedback, Evaluation, and Recognition of Community Staff and Participants

Although evaluation and feedback to employees is always important, the creation of a systematic feedback process for community staff is especially important for ensuring high-quality data collection and promoting high staff morale.

The role of the recruitment/field supervisor was crucial in the feedback system. She was able to develop a team attitude among community staff while implementing daily supervision (including verification phone calls and visits) to ensure data quality. Her dedication to the community was a key aspect in her credibility with other community staff.

In the lung-function data collection and the indoor air-sampling work, CAAA academic researchers met with Airwatch distributors to share the previous season's graphs, depicting the child's Airwatch blows. This allowed distributors to see how well the child had followed the procedures and, consequently, how well they had trained the child. For the indoor air sampling, academic researchers met with the CESs and the field supervisor prior to each collection to review the previous data. During these sessions, the researchers highlighted where the data collection was going well and reinforced techniques to improve the data gathering or the air quality sampling.

A key aspect of this feedback system was ongoing recognition of community staff. The CESs were recognized through memorandums praising their work (placed in personnel files); applause and roses at Steering Committee meetings; a newsletter column about each of them; time off after data collection periods; and a salary upgrade midway through the project.

This feedback system was also extended to the families themselves. All families received a summary report of their child's Airwatch results and an explanation of what they meant. Similarly, those families participating in the intensive indoor sampling received a summary report of the sampling in their home in a feedback meeting held at the end of all the seasonal intensives. These summary reports were developed in conjunction with the Steering Committee, who encouraged us to "break it down," to make them clearer and more understandable, consistent with the CBPR principle of dissemination of information in clear, respectful language.

Use the Specialized Knowledge of Community Members and Follow Their Guidance

CAAA brochures, questionnaires, recruitment plans, IAS family recruitment, and incentives are all examples of materials or plans initially drafted by university staff and subsequently improved based on community input. Community partners and community staff have intimate, invaluable knowledge of community circumstances, culture, comfort levels, fears, and attitudes, and

they have important contacts that can be utilized in all project phases. Listening to community partner and staff ideas enhances the research and helps build community capacity. As part of this process, it is important to recognize that working in a partnership requires flexibility and adaptation from what may have been initially proposed. Our partners were also involved in hiring decisions, by developing job descriptions and serving on interviewing and selection teams, thus also increasing their ownership.

Use Modeling Techniques and Peer Presenters When Training

As suggested in the literature (Vella, 2002), the use of adult learning techniques (i.e., modeling, peer presenters) was very effective in training our community staff. For the Airwatch and interviewer training agendas, encouraging former staff to talk about their experiences and give advice to new staff was helpful and seen as credible. Ideas from staff about how to reach the hard-to-reach families as well as opportunities to laugh about their experiences enhanced the training for all interviewers and helped increase motivation. Positive responses to the training reinforced for us the importance of role modeling and peer presentations in training activities.

Track the Hiring of Community Staff Members as an Effective Way to Build Trust While Also Enhancing Community Capacity

We suggest keeping track of the numbers of community members hired as staff to help calculate the additional and more immediate benefits to the community of a research partnership. These benefits are economic in terms of jobs, and capacity building in terms of skill building of community members. The information is useful to share at community presentations and other dissemination activities.

► CONCLUDING COMMENTS

The results of the intervention and the epidemiological findings of CAAA will be reported in future articles. The community partners and community health workers will continue to participate in interpreting the data, disseminating the findings, and designing environmental health education interventions to improve the quality of life for families in Detroit. Community lay workers can be an important part of increasing knowledge and understanding of phenomena and can add tremendous

value to health education and epidemiological research, and in turn, lay workers can benefit from participation in projects such as these by increasing their skills and capacity. This case study is a reminder that practitioners and researchers need to look to the community for invaluable resources sometimes ignored, overlooked, unacknowledged, and untapped.

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