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COMMUNITY ENGAGEMENT IN CHILDREN'S ENVIRONMENTAL HEALTH RESEARCH

Barbara L. Brenner, DrPH, LMSW and Melissa P. Manice, MPH

Mount Sinai School of Medicine, New York, NY

Abstract

Community engagement strategies and skills can build trust and reduce historical mistrust between researchers, communities and populations being studied, as well as contribute to the quality of study designs, methods and dissemination of findings. This review paper discusses why community engagement is of increasing importance in children's environmental health research, describes models and the continuum of methods that are used and discusses their challenges and benefits. Two case studies, representing different study designs and using different community engagement models and methods, and lessons learned from these cases are described.

Community engagement methods are best understood on a continuum based on the degree to which community members or representatives of community populations are involved in research planning, decision making and dissemination. Methods along this continuum include community consultation, community based participatory research (CBPR) and community consent to research. Community engagement knowledge and skills are especially important in the conduct of children's environmental health research with its emphasis on reducing environmental risks at the community level; the increasing focus on genetics and gene-environment interactions; and the importance placed on translation of scientific results into behaviors and policies that protect the community. Across study designs, whether qualitative survey research, an observational epidemiology study, or a randomized intervention trial, understanding community interests, norms and values is necessary to describe attitudes and behaviors of specific population groups, build evidence of cause and effect between environmental exposures and health and/or that demonstrate the effectiveness of interventions to reduce risks.

Keywords

Community engagement; community consultation; community based participatory research; children's environmental health

"Sometimes as scientists we make assumptions and don't rethink assumptions to see how they fit in a natural situation.Community people, because they are looking at it from a fresh perspective, will question the assumptions in a way that actually improves the science....." 1

Rising rates of chronic illness and disability among children have stimulated researchers and communities to look for causes and mechanisms that have an environmental etiology. Childhood asthma, obesity, learning disabilities, cancer, male infant sex organ abnormalities and earlier puberty in girls have all been associated with exposures to polluted air, lead,

Corresponding author: barbara.brenner@mssm.edu; tel, 212-824-7025; fax, 212-824-2324 –Fax.

Postmail addresses for both

Department of Preventive Medicine, Mount Sinai School of Medicine, 1 Gustave L. Levy Place, Box 1057, New York, New York 10029

pesticides and other chemical products such as mercury. These pollutants and chemicals are consequences of the built environments in which we live, such as mold in housing and schools, poor access to healthy food, and lack of safe accessible physical activity resources.²⁻¹¹ There is growing evidence that children are more susceptible than adults to environmental exposures with life-long consequences.

The causation and aggravation of these problems is multi-factorial, requiring researchers to investigate the interaction of environmental exposures with socioeconomic conditions and cultural norms of communities from which research participants are recruited. Children from all socioeconomic backgrounds are affected, but the burden of illness is often borne disproportionately by children from low-income communities and communities of color.

Community engagement skills are especially important in children's environmental health research because of their emphasis on reducing environmental risks at the community level, increasing focus on gene-environment interactions, and the importance of translating scientific results into behaviors and policies that protect the community. Understanding community interests, norms and values is necessary to engage a sufficient number of children/families to build evidence of cause and effect relationships between environmental exposures and health and/or to build evidence that an intervention to reduce exposure is effective.

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Community engagement is a strategy to build trust between researchers and the population groups and communities asked to participate in studies. At the same time, many researchers have recognized that community involvement can improve the quality, relevance and impact of their research.¹²⁻¹³ Collaboration with community members and their representatives has given researchers, often from different cultures and socioeconomic backgrounds from study participants, new perspectives and respect for community interests and values. This has led to improved study designs and methods, higher recruitment and retention of study participants, and the production of valid and more meaningful results.¹⁴ Communities also benefit when technical assistance and educational resources are made available to organizations and residents; as well as when researchers work in partnership with the community to advocate for policies to reduce environmental risks and improve community health.

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The National Institutes of Health (NIH), the Centers for Disease Control and Prevention (CDC) and the Environmental Protection Agency (EPA) have recognized the need for greater community involvement in the processes that shape research and translate it into practice.¹⁵⁻¹⁸ Recently, the Clinical and Translational Science (CTSA) awards have required plans to support faculty development in community engagement, particularly those underrepresented in research and/or facing health disparities, and to build community capacity to engage in research.¹⁹

A continuum of community engagement models and methods have evolved in the last two decades, but no consensus exists about the most appropriate method of involving

communities in different types of research whether cross-sectional, longitudinal observational studies, intervention studies, clinical trials or qualitative research.²⁰ This paper will describe several approaches used to engage communities and community partners in children's environmental health research, with examples from two case studies. We will also discuss the benefits and challenges encountered, and lessons that can be applied to future community engagement strategies and methods.

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BURDEN OF MISTRUST AND CHALLENGE OF COLLABORATION

Mistrust has been generated by valid community concerns that well-intentioned researchers have “used” communities as laboratories without engaging them in understanding the benefits and risks or in “defining priorities, planning studies, or developing implementation strategies.”²¹ Negative perceptions of research have led some community leaders to refuse to participate in what has been called “helicopter projects” or “drive-by research.”²² When communities perceive themselves as vulnerable due to race, ethnicity, language, income and/or educational levels, it affects participation rates and importantly, the applicability of results. Negative attitudes about research participation by African Americans are a legacy left by the Tuskegee Institute Study of Syphilis in Black Men (1932–72). A recent example of misunderstanding and mistrust, reported widely in the national press, was the use of DNA samples from the Native American Havasupai tribe by Arizona State University to answer research questions that tribal members had not approved in advance.²³

Community members sometimes object that researchers are more vested in personal and professional gain than in benefiting the communities they study or the larger society.^{24–25} This is an ongoing complaint when communities and research participants receive no information from investigators about results, their interpretation, or how the results might benefit the community. When communities and their representatives are engaged from a study's inception, it is more likely that the length of time required to collect and analyze data and to prove or disprove cause and effect will be understood.

Researchers struggle with the issue of “control.” Children's environmental health research at the population or community level has been led by scientists trained in epidemiology and toxicology, sciences that require rigor in study designs, methodologies and data collection and analyses. There has been concern that community involvement could compromise this rigor. Some epidemiologists have called for a paradigm shift arguing that the risk-factor paradigm overemphasizes the individual level of risk to the exclusion of other organizational levels of risk.^{26–27} This view asserts that health and disease must be studied in a social context and with increased community participation and “implies working across disciplines and with the population itself, in defining variables, designing instruments and collecting data(qualitative and quantitative) that reflect the ecological reality of life in that population as people experience it.”²⁸ Within such collaborations, epidemiologists would not be required to surrender rigor, but they would be required to share power.²⁸

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Environmental studies have become interdisciplinary, incorporating expertise in genetics and the behavioral sciences. The knowledge and skill needed to achieve successful community engagement in research is increasingly derived from pooling theories and methods from many new disciplines--anthropology, behavioral psychology, community organizing, health education, sociology, social work and marketing and communications.²⁹

MODELS OF COMMUNITY ENGAGEMENT

Community is a fluid concept; individuals may belong to multiple communities at any one time. We use the following definition: a group of people united by at least one but perhaps more than one common characteristic, including geography, ethnicity, shared interests, values, experience or traditions.”¹⁸ Chinese Americans living in Flushing, Queens could be considered a community as might African Americans residing in Harlem or Hasidic male Jews in Brooklyn’s Boro Park. Individuals living in a geographically distinct neighborhood can also be considered a community as they share a common physical and social environment, such as the population of East Harlem. Factors to explore to understand and describe a community are:

- People (socioeconomics and demographics, health status risk profiles, cultural and ethnic characteristics)
- Location (geographic boundaries)
- Connectors (shared values, interest, motivating forces)

- Power relationships (communication patterns, formal and informal lines of authority and influence, stakeholder relationships, resource flows)¹⁸

Models of community engagement in biomedical, public health and social science research incorporate various degrees of communication and partnership with researchers in project development, design, implementation and dissemination. A typology of community engagement models and methods used to achieve their goals are summarized in Table 1.³⁰⁻³⁶

The “exchange” principle is embedded in and basic to each of these models. This principle asserts that all community engagement models in research should create and maintain exchanges of value to the community or population being studied in the form of either improved health or prevention initiatives, education, community capacity building and/or policy advocacy.²⁹

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Selecting the appropriate model is one of the challenges faced by researchers when engaging with populations and communities from which they wish to collect data. A decision must be based on the particular community or population group, the nature of the research and the likely impact of the research on the community. Another consideration is the degree to which the researcher can commit to long-term engagement with the particular community and the need to build trust with community leaders and residents. Community based participatory research (CBPR) is different from community placed research which does not significantly involve the community in study design and methodology, but where community representatives are passive participants, reacting to researchers as members of Community Advisory Boards or merely assisting in recruitment.²²

CASE STUDY I: GROWING UP HEALTHY IN EAST HARLEM: A CBPR STUDY

Growing Up Healthy in East Harlem was a two-arm community intervention trial to test the feasibility and effectiveness of Integrated Pest Management (IPM) in East Harlem, Manhattan, New York City. It illustrates CBPR principles, methods and outcomes.³⁷ East Harlem, a low-income, multiethnic community of 117,000 is 52% Hispanic and 38% African American (U.S Census, 2000). The study was one of five projects in the NIEHS/EPA funded Mount Sinai Center for Children’s Environmental Health and Disease Prevention Research, whose overriding goal was to identify, elucidate and prevent developmental deficits resulting from exposures to environmental toxicants in the inner city. Exposures of concern were organophosphate pesticides used extensively in New York City.

The study grew from a shared concern by community health centers and medical school environmental scientists and pediatricians about the high prevalence of childhood asthma and prenatal and early childhood exposure to pesticides used to control cockroaches. Health center and medical school representatives worked collaboratively for 25 years on service delivery issues and were active members of a community health coalition that addressed the high rates of asthma among East Harlem children but had never worked together on a research project. Most residents were renters, living in poorly maintained tenement buildings and public housing projects. Pesticides were applied by tenants and housing managers to control endemic cockroach infestation but were not successful at reduction or elimination.

Pesticides in heaviest use were organophosphates, chlorpyrifos and diazinon, (both were subsequently banned for sale) and the carbamate propoxur. Chlorpyrifos has been shown in rodent studies to be a developmental neurotoxicant, a finding confirmed in additional investigations.³⁸⁻⁴¹

Building the Research Partnership: Guiding Principles

Study investigators hypothesized that exposure to developmental toxicants in the inner city could be reduced through education, action and behavioral change. To be effective, these methods needed to be culturally and linguistically appropriate, affordable, and developed in close collaboration with East Harlem community representatives. To achieve this, a research partnership was formed with two East Harlem Federally Qualified Health Centers (FQHC) providing primary and prenatal care to primarily low-income Puerto Rican, Mexican and African-American families. Both health centers were governed by boards with community resident majorities, were major employers of community residents, and were directed by administrators who were long-time residents or community health workers. Both were skeptical of participation in research that might confuse, intrude or exploit their patients. A five-year process of partnership building transpired with many challenges to both community and academic partners. This was the first time that all research partners were applying CBPR principles of shared decision-making and power sharing. Guiding principles and protocols adopted were:

- Agreement that a study had to provide concrete benefits to participants. The choice of Integrated Pest Management (IPM) as an intervention to reduce cockroaches and pesticide use in the homes of pregnant women would provide a benefit. A comparison group study design was chosen comparing a convenience sample of pregnant women from one center (the intervention group) with a convenience sample from another center (the comparison group). The comparison group received home injury prevention, and the option of receiving IPM at the end of the study. Providing an intervention of value to the comparison group was a condition of participation for that health center.
- Agreement that community health centers would be study recruitment sites with field staff who were bilingual community residents and employees of the centers, but jointly interviewed and selected.
- Agreement to include funding support to the health centers, through sub-contracts, for staff, supervisory time and administrative overhead, a condition of participation.
- Pediatricians from both Centers were invited to be co-investigators, working with the study PI to oversee research at each site, to be members of the larger Center research team that met monthly, and eventually to co-author papers. Weekly meetings of the PI, co-PIs and health center staff were held initially to review and agree upon research protocols, including environmental and biological sampling methods, consent forms and recruitment/retention strategies and incentives.
- Questionnaires received collective review and approval. In addition to medical school IRB approval, each center also conducted their own IRB reviews.

Community partners reviewed written materials for recruitment, intervention and community dissemination. Partners formed a Community Advisory Board of twenty community stakeholders that met semi-annually to advise the team on pesticide use practices and housing conditions and to help design and disseminate broader community-wide education. This Board functioned as a community consultant to the community-academic research partnership, but was not a decision-making body.

Study Design, Methods and Results

One hundred thirty-one East Harlem pregnant women enrolled in the study from September 1999 to June 2002, seventy-six recruited to an intervention (IPM) group and fifty-five recruited into the non-intervention comparison group. At six-month follow up, eighty-eight or 67.2% of the households remained in the study. The major reason for loss to follow-up was moving out of East Harlem.

A detailed description of study protocol, methods and outcomes are discussed in detail elsewhere.³⁷ Following consent, participants in both groups answered detailed questionnaires on home environmental conditions and received home visits to monitor pesticide levels, collect baseline information on cockroach infestation levels, and measure pesticide levels through sampling urine, household air, dust, hand and toy wipes. Roach levels were assessed through glue surface cockroach monitors. Individual IPM plans were developed for each intervention household. A bilingual, bicultural team - health educator, community outreach worker, handyman and IPM consultant - worked with the head of household to teach IPM, sealing cracks and crevices, plugging holes, and applying low-toxicity baits and gels to kill cockroaches and their eggs. Comparison households received no IPM education or application, but did receive a home injury prevention intervention, including child proofing tools and techniques. The comparison group was offered IPM at the end of the study.

The IPM intervention was effective in reducing cockroach infestation in low-income, urban households, even in buildings in need of repair. Residents and landlords learned to apply and maintain IPM at a reasonable cost. Three quarters of the families in both groups had cockroach infestation at baseline and 60% reported that pesticides had been applied in their homes during pregnancy. After six months there was a marked and significant decrease in cockroach infestation among intervention households (from 80.5% to 39.0% of households; $p < 0.0001$, McNemar's Test). By contrast, comparison households showed no reduction (from 78.1% to 81.3% of households) (Table 2).

Costs of building-wide IPM in a typical East Harlem apartment building were estimated, including repairs, and were comparable to the costs of traditional, chemically based pest control not including repairs. Guided by these results, a community-wide campaign to adopt IPM and reduce pesticide use was carried out by the research partnership in 2003. Study investigators testified before the New York City Council in support of Intro 328A, requiring neighbor notification of outdoor pesticide spraying and Intro 329A, requiring New York City to use alternatives to chemical spraying in all city-owned property, including schools, city agencies and contractors. Both proposals are now law.

Benefits of this Community Based Participatory Research Model

The Growing Up Healthy in East Harlem community-academic partnership produced substantial concrete benefits of better study design and more effective methods to gather "sensitive" quantitative and qualitative data from low-income households who had not previously participated in research. Community partners acted as an important bridge between study investigators and a culturally, linguistically and economically diverse population. Trust between the community health center staffs and their prenatal patients was the key element to successful study recruitment and retention.

Community partner insight shaped a realistic study design. The original design was modified to give the comparison group an intervention of value - a home injury prevention intervention. This was instrumental in ensuring an adequate sample size. Community partners reviewed study questionnaires for sensitivity to language and literacy levels. Guidance received in methods of exposure data collection led to adoption of air sampling

rather than dust sampling to determine pesticide exposure levels because community partners knew that most households had no carpeting and protected their furniture with plastic covers.

Community partners helped investigators translate study results and information about pesticide risks and alternatives to the broader community, spearheading one of the first integrated pest management community education workshop programs in New York City with building owners, managers and superintendents as well as community residents. These programs and policy initiatives reinforced how the community benefited from research and led to community support for future children's environmental health research in East Harlem.

[callout] In the Growing Up Healthy in East Harlem study, community partners acted as an important bridge between study investigators and a culturally, linguistically and economically diverse population. They also helped investigators to shape a realistic study design and translate study results and information about pesticide risks and alternatives to the broader community, thus spearheading one of the first integrated pest management community education workshop programs in New York City with building owners, managers and superintendents as well as community residents.

Challenges and Lessons Learned

Lack of Trust and Respect: Institutional History—Building and maintaining trust between study investigators and community partners is an ongoing challenge because of historical experiences of collecting data without sharing results or providing tangible benefits to the community.^{12, 42} In the Growing Up Healthy study, community partners respected the study PI and research team and acknowledged the value of shared decision-making, in addition to the benefit of IPM to their clients and the community. However, frustration, if not mistrust, in the institution itself often surfaced, based on non-study issues such as problems making referrals to the hospital for specialty care; medical school researchers experienced the tension but had little influence to solve these problems.

Time and Resources Needed to Make Collaboration Work—Effective academic-community partnerships require time, resources and infrastructure support to establish and maintain trust, attend meetings, jointly participate in all phases of the research process, and foster capacity building for all partners. This was difficult to sustain for the Growing Up Healthy community partners who had limited time and resources to stay involved in the details of implementation, data analysis and publication. Research grants have often inadequately compensated community partners for administrative costs or as co-principal investigators and there are opportunity costs for time taken away from other job responsibilities.^{43, 44} While Growing Up Healthy community partners did receive funding for time and effort it was not sufficient to free time of their leadership to be day to day research partners. Researchers have found that the CBPR model is more labor intensive than they expected, taking time away from publishing and undervalued for promotion and tenure purposes.⁴⁴ Building a collaborative, equitable partnership requires skill and commitment from all partners to foster participation and shared decision-making but often falls short of the ideal due to the limitations discussed above.

Institutional Constraints—Institutional constraints emerge in conducting CBPR.^{12, 20} For example, the equality of ownership principle may not be understood by university IRBs who require that co-investigators and research staff from community partnerships fit into traditional job descriptions and educational degrees, precluding non-professionals from being recognized as equal partners. There is a need for flexibility to revise protocols and

simplify study methods based on community input. In this CBPR study, the medical school's IRB did respond to changes suggested by community partners.

Lack of Training and Experience in Conducting CBPR—There is now a substantial literature on how to carry out CBPR methods, but many researchers have had no training or mentoring and limited opportunity to engage in learning opportunities.⁴⁵ This is particularly challenging when community involvement is a requirement from the funding source. Likewise, community partners have not been trained to do research, and often their experience with research has not been positive. This CBPR study provided an early training ground for academic and community partners to learn how to establish realistic expectations for partnership roles and outcomes. Community partners, in this case two FQHCs, established stronger internal IRBs and standards for deciding when they would collaborate on future research partnerships.

Different Emphasis on Goals, Values, Priorities and Perspectives—Community and academic partners may differ in their emphasis on goals, values, priorities and perspectives.¹² Community partners may be eager to implement interventions and disseminate preliminary results. Researchers are frequently concerned that the premature dissemination of results may contaminate study findings and lead to scientific criticism, thereby affecting future funding and ability to publish.²⁰ This was a tension in Growing Up Healthy when community partners were eager to get final study results out to the community and questioned long delays associated with data analysis and investigators caution regarding data interpretation. We found that when members of partnerships have different values, beliefs, and cultures, it is important to acknowledge that there is no standardized partnership operation approach, though they must consider and accommodate diverse perspectives.

CASE STUDY 2: THE NATIONAL CHILDREN'S STUDY, A PROSPECTIVE BIRTH COHORT STUDY OF 100,000 U.S. CHILDREN AND THEIR FAMILIES

Study Origins and Methodology

The National Children's Study (Study) is a longitudinal observational study of 100,000 children and their families that will recruit women of childbearing age before conception or during pregnancy and then follow their children for up to 21 years. The study will examine the separate and combined effects of environmental exposures (biological, chemical, physical and psychosocial) as well as gene-environment interactions on pregnancy outcomes, child health and development, and precursors of adult disease.⁴⁶ Participants will be recruited from over 100 locations throughout the United States based on a probability sample representative of U.S. births. The study design was conceived nationally by a cross-section of scientists and is being implemented locally by leading academic institutions for each location.

Due to the Study's scale and a complex sampling design, CBPR could not be employed in the design or implementation of this longitudinal cohort study. However, a community engagement strategy was essential as the basis for successful recruitment and retention of study participants. Community engagement methods closely resembled a "community consultation" model in Table 1, an approach that elicits input from community representatives in the target communities about social and cultural attitudes, perceptions, and beliefs related to the research project. However, there were no formal partnerships or dialogue in the study design or methodology.

Seven Vanguard locations were selected in October 2005 as the first to launch the Study, including Queens County, New York City, the most ethnically diverse county in the United

States. Over 138 languages are spoken in Queens, and 46% of Queens residents were born outside of the United States.^{47,48} Mount Sinai School of Medicine was selected as the lead institution to conduct the study in Queens with collaborating co-sponsors - the New York City Department of Health and Mental Hygiene, Mailman School of Public Health of Columbia University, Columbia College of Physicians and Surgeons and the New Jersey College of Medicine and Dentistry. Participant recruitment in Queens commenced in January 2009. The study sample was determined by a three-stage sampling design implemented by National Center for Health Statistics statisticians, and is described in detail elsewhere.⁴⁹ Study locations were chosen to achieve representation of all children born in the U.S. and in general, corresponded to a single county. Final sampling units were sub-neighborhoods (segments) representing equal births, from which women of child-bearing age were invited to participate. A standardized door-to-door enumeration and recruitment method was chosen across all seven sites. Community outreach, a key factor in support of recruitment, could be tailored for each site. Community engagement methods outlined here are specific to the Queens site. Because of the NCS organizational and operational complexity, study implementation posed many challenges in Queens and across the six other Vanguard Centers. Goals for community engagement were to:

- Find community partners who could commit to being community “consultants”.
- Build Study legitimacy among leaders and members of the diverse ethnic, religious and cultural communities of Queens.
- Establish visibility and legitimacy in the small geographic segments that were randomly selected to recruit and enroll eligible women.
- Retain the interest and investment of study participants and our community partners for a long term study.

Early Engagement of Community Partners and Key Stakeholders: February 2005–May 2007

Queens Vanguard Center investigators began the community engagement process in February 2005 prior to submitting the Study application, reaching out to four respected community based organizations representing a cross section of the county’s diverse constituencies. Engaging key stakeholders that captured the range of cultural and ethnic diversity in Queens was essential. These included a health coalition representing over 40 ethnic and language groups; a coalition of African American churches; and a federally qualified community health center representing an isolated section of the county. If funded, these organizations would act as paid consultants who would serve as our guides to gather in-depth information about the segments and to introduce us to community stakeholders with influence in the targeted recruitment segments. A fourth organization - a coalition of prenatal provider and community based organizations - agreed to serve as an unfunded partner.

The Study was awarded in October 2005 but community partnerships were tested when Federal funding was eliminated, creating a hiatus from February 2006 through May 2007. During this uncertain period, study investigators tried to be as transparent as possible about the Study’s future while at the same time assuming an active and visible community role and acting as a source of information and expertise to community groups on children’s environmental health.

The Long Road to Study Launch: Building Community Legitimacy and Understanding Cultural Sensitivities: May 2007 – January 2009

In May 2007, the Study’s funding stream was renewed. Segment selection, the listing of all segment-based households and development of a data system would delay active recruitment

for eighteen months. With our community partners, we devised a multi-step strategy to build Study awareness, legitimacy and support. Our message of engagement was “Queens First,” as Queens was one of two counties in the nation where this major health Study would first be launched. The first step was to gain endorsement from key social, civic and political leaders and organize a Queens Vanguard Center Community Advisory Board (CAB). Every community’s social, civic and political structure is unique. In Queens, we sought the endorsement of an elected and widely respected Borough President, a key opinion leader, who introduced us to the fourteen community planning boards that oversaw city services in every Queens neighborhood. Representatives from each of the Boards were invited to be founding CAB members as were our community partners and the Borough President’s office. A twenty member board, representative of the cultural, ethnic and geographic diversity of Queens, met for the first time in November 2007 and continues to meet quarterly. A co-investigator moderated meetings, as CAB members did not want to elect leadership or establish formal structures and by-laws. Our second step was to gather as much information as possible about the eighteen segments; we enlisted our community partner organizations to walk the streets to gather it. Information gathered included predominant ethnic and/or religious group membership, languages spoken, and places of worship and schools that interact with segment residents.

The CAB, while unable to influence study design and methodology, did influence strategies and messages for community engagement and study recruitment and. advised on cultural and religious sensitivities, such as religious holidays to avoid, and acceptable behavior and dress protocols. They reviewed print materials for sensitivity to Queens politics, culture and literacy levels and advocated for translation of recruitment and Study materials into seven major languages. They identified Queens-specific media outlets and segment-specific community organizations. They recommended qualified community members from a cross section of language groups and nationalities to work as field staff.

Challenges of Embedding the Study in the Community: January 2009 – June 2010

We commenced recruitment in January 2009, announcing the Study at a highly visible event, the Queens Borough President’s annual “State of the Borough” address, attended by an audience of elected officials, community leaders and local media. Press coverage was extensive, providing Queens-wide recognition for the National Children’s Study. However, once we began knocking on doors during the first months of household-based recruitment, we learned that county-wide efforts and pre-launch community engagement with stakeholders did not trickle down to Queens households at the segment level. We learned that urban social networks from diverse ethnic, religious and language backgrounds were not geographically-based. People living on the same block or building do not know or socialize with each other but are often organized around meaningful non-geographic communities. This reality drove the next phase of community engagement- targeted outreach to faith-based, school-based and civic organization leaders who we asked to deliver spoken or written study endorsements and provide their constituents with multilingual printed materials. Constituency buy-in was more easily obtained because messages and materials were delivered from a trusted community member. Men, many from patriarchal cultures, were often gatekeepers at the doorstep, leading us to engage male leaders of large mosques and synagogues. The greatest unanticipated challenge was gaining access to large middle and upper income residential communities - locked buildings with an attended lobby. Obtaining access required extensive outreach to property managers and condominium boards and access to conduct door-to-door enumeration was rarely granted.

As we contacted leaders from these social networks, individual and institutional support for the study was enhanced by providing something of value to the community. In particular, community organizations wanted more information on environmental exposures and health

risks during pregnancy and childhood. Workshops on environmental exposure topics such as alternatives to plastics, pesticides, and everyday asthma triggers were delivered at local libraries, schools, day care centers, places of worship and community centers. Workshops reinforced the aims of the National Children's Study, enhancing the association between the Study and children's environmental health. We also developed newsletters, resource cards and fact sheets on environmental risks and health. These efforts enhanced Study recognition at the segment level, and ensured that study information was disseminated to eligible participants and their support networks.

Lessons Learned

Importance of Understanding Community Values and Behavior—In a longitudinal study where eligibility is defined by geographic parameters, segment-level community buy-in is essential. An ongoing challenge in our urban multi-cultural communities has been identifying trusted sources of information in the community, including community spokespersons and high-volume local news outlets. Our on-the-ground data collectors, who were enumerating all eligible households, systematically identified in-segment key informants who expressed support for the Study. This grassroots community-informed outreach was the best strategy during active participant recruitment. Key informants provided segment-specific information that greatly assisted in targeting outreach to eligible participants. Hiring data collectors and outreach staff who were racially and ethnically similar to the in-segment populations was also vital in establishing segment-specific trust.

Importance of Early Qualitative Assessment—Although we obtained early support from key Queens-wide organizations, we learned that buy-in from leadership did not translate into awareness of the Study at the segment level. It was necessary but not sufficient. Qualitative information obtained through focus groups with segment residing women of child-bearing age and their support networks would have provided much better information and guidance on attitudes toward research, and an awareness of how and where stakeholders obtain information at the segment level. Our initial plan was to conduct focus groups but at that time use of federal dollars for this type of research was not allowed. Because Queens residents operate in distinct and often disparate communities, qualitative assessments of key segment-level social networks prior to active recruitment is imperative.

Research must be a bi-directional activity—Sustaining community support is an ongoing challenge of longitudinal studies. Meaningful and valid results at both the community and participant level may not be available for years and community benefit is not concrete. Our community engagement work emphasized action-based and bi-directional strategies for engaging individuals and communities. Engagement efforts were met with little success when simply conveying Study messaging and asking for support. Creating and maintaining an exchange of value to the community, such as education and community capacity building, is an effective community engagement strategy. The environmental exposure workshops exemplify the successful bi-directional outreach employed in the National Children's Study Queens location.

CONCLUSION

Children's environmental health studies using CBPR and community consultation models require commitment to community outreach and engagement in the study design and planning phase. Growing Up Healthy and the National Children's Study utilized different strategies and methods to ensure that community engagement was a bi-directional activity. In the case of Growing Up Healthy, the community partners guided study design,

methodology and implementation. In the National Children's Study, community leaders and key informants were influential in shaping recruitment strategies.

Both studies demonstrate the importance of the exchange principle in gaining and sustaining community support and advancing study recruitment, particularly among linguistically and culturally diverse populations frequently underrepresented in research. This principle can apply in all community engagement models. In the research planning phase, an assessment of community need and of the exchange between researchers and the community must be conducted. This consideration is particularly important in studies such as the National Children's Study, where study data cannot be offered as a community resource and incentives such as participant compensation are predetermined. In Queens, non-monetary opportunities were guided by community-identified need for technical assistance and environmental education. Exchanges will differ based on the nature of the study design and on the community that is participating in the research. What is offered in the exchange will also differ, but can be classified as monetary or as goods and services, such as technical assistance and skills training. The utility of this bi-directional relationship in creating novel study designs and methodologies, in supporting effective participant recruitment and retention, in enhancing trust in and the reputation of researchers, and in facilitating future research in the community cannot be underestimated.

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Figure 1.

Percent of intervention households (median and inter-quartile range) with any cockroaches during a 6 month period. Pesticide Intervention Project, New York City, 1999–2002. There is a significant decrease in the number of households with any cockroaches in the intervention group at baseline compared with the 6 month follow up. ($p < 0.0001$, trend test) Note: $N = 41$ except for 3 Month; $n = 40$.

Table 1**A Continuum of Community Engagement Models**

	<u>Community Consultation</u>	<u>Community Participation/Community Based Participatory Research</u>	<u>Community Consent</u>
Description	Eliciting feedback, advice, criticism from communities about their attitudes and perceptions of research, the research question or knowledge translation; no formal dialogue or partnerships between researchers and the community or their representatives regarding study design and methods. Does not include asking for approval or permission.	Equitable involvement between researchers and those affected by the issue under study in all aspects of the research process; dialogue and exchange between community representatives or members re values, consent, study design, methods and dissemination; formal agreements between community and researchers regarding rules of engagement or partnership.	Soliciting approval or permission to conduct a study within a community; formal consultation process with communities that are sovereign states or highly organized political structure to approve research.
Methods	<ul style="list-style-type: none"> • Focus Groups • Community Surveys • Town Hall Meetings • Community Advisory Boards 	<ul style="list-style-type: none"> • Community-Academic Research Partnerships • Community Action Boards 	<ul style="list-style-type: none"> • Formal agreements • Oversight by Councils or Committees of community leadership
Examples	Case Study #2 - the National Children's Study, Queens Vanguard Center, Queens, New York	Case Study #1 - Growing Up Healthy in East Harlem, a community intervention study driven by a community-academic research partnership	Process often used with Native American communities and traditional cultures internationally

Table 2**Results of IPM Intervention Trial**

Presence of Cockroaches at Baseline and 6 Months in Control and Intervention Households. Pesticide intervention project, NYC, 1999–2002.

	Followed Study Population			
	Intervention (n=41)		Control (n=32)	
	Baseline	6 month follow-up	Baseline	6 month follow-up
% of Households with Any Cockroaches	80.5% *	39.0% *,**	78.10%	81.3% **
Median # of Cockroach Monitors Placed	8	8	8	8
Median # of Positive Cockroach Monitors	3	0	5	4
Median % of Positive Cockroach Monitors	25.00%	0.00%	54.00%	40.00%

* At the 6-month follow-up, intervention households reported a significant decrease in the percent of households with any cockroaches ($p < 0.0001$ McNemar's Test).

** At the 6-month follow-up, there are significantly fewer households with cockroaches in the intervention group than in the control group ($p < 0.001$).