



Opening Doors and Building Capacity: Employing a Community-Based Approach to Surveying

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ABSTRACT *Although many community-based initiatives employ community residents to undertake door-to-door surveys as a form of community mobilization or for purposes of needs assessment or evaluation, very little has been published on the strengths and weaknesses of this approach. This article discusses our experience in undertaking such a survey in collaboration with a coalition of community-based organizations (CBOs) in the South Bronx, New York. Although resource constraints limited the already-strained capacity of the CBOs to provide supervision, the CBOs and community surveyors helped us gain access to neighborhood buildings and to individuals who might otherwise have been inaccessible. The survey process also contributed to the coalition's community outreach efforts and helped to link the CBO leadership and staff more closely to the coalition and its mission. Many of the surveyors enhanced their knowledge and skills in ways that have since benefited them or the coalition directly. The participating CBOs continue to be deeply engaged in the coalition's work, and many of the surveyors are active as community health advocates and have taken leadership roles within the coalition.*

KEYWORDS *Community engagement, Community-based research, Participatory research, Public health partnerships.*

INTRODUCTION

As part of a national program to help reduce racial and ethnic disparities in health, the Centers for Disease Control and Prevention funded an effort in the South Bronx, New York, led by the Institute for Urban Family Health, to reduce morbidity and mortality resulting from diabetes and related heart disease. Racial and ethnic disparities in diabetes outcomes have been well established; see generally Black.¹ In this predominantly minority community, the hospitalization rate for diabetes is 55.69 per 1,000 residents aged 40 to 64 years compared with a rate of 24.80 citywide.² The mortality rate for diabetes for women aged 18 to 64 years is 20 times higher than in the predominantly white Upper East Side of Manhattan, a 10-minute subway ride away.³

The coalition that formed to carry out this initiative (Bronx Health REACH) includes a wide array of organizational members: social service agencies, health care

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providers, a housing development corporation, an after school program, legal advocacy groups, and over 20 churches. Its initiatives include a nutrition and fitness program, a faith-based outreach program, a training program for community health advocates, a public education campaign, and a legal and regulatory initiative. Working closely with the coalition since its inception, the Center for Health and Public Service Research at New York University has provided general research support, formative evaluation, and impact analysis. As part of this work, the center developed and oversaw the fielding of a door-to-door survey of diabetics living in the South Bronx, administered by community residents.

The purpose of the survey was three-fold: (1) to obtain baseline data to measure the impact of the coalition's activities on the knowledge, attitudes, beliefs, and behavior of community residents with diabetes; (2) to learn more about the problems faced by diabetics in this community to help shape the coalition's interventions; and (3) to contribute to community mobilization and capacity building by directly involving community-based organizations (CBOs) and residents in designing and fielding the survey and in interpreting and disseminating results.

Although many community-based initiatives undertake such door-to-door surveys as a form of needs assessment or for evaluation purposes, very little has been published on the practical and methodological issues raised by this approach. This article discusses the lessons we learned from the fielding of the survey: the strengths and weaknesses of this methodology and its impact on our survey sample and data collection. Our hope is to provide guidance to others who may be considering this approach.

METHODOLOGY

Over the course of a 6-month period, we surveyed 1,086 adults (246 of whom had been diagnosed with diabetes) residing in the Highbridge, Morrisania, West Tremont, and Morris Heights South Bronx neighborhoods in which the coalition is working (ZIP codes 10452, 10453, 10456, and 10457). To be eligible to participate in the survey, a respondent had to be at least 18 years old and have lived in the neighborhood for at least 6 months.

The survey was done in person, rather than by telephone, because of the problem of lack of telephone coverage and unlisted telephone numbers in low-income neighborhoods.⁴ We were particularly concerned that with the growing use of cellular telephones, we would miss many people whose telephone numbers could not be tied to a geographic location.

The survey instrument was developed using questions from existing surveys, including the Behavioral Risk Factor Surveillance System Diabetes Care Profile⁵ and the diabetes portion of the Agency for Healthcare Research and Quality's Medical Expenditure Panel Survey.⁶ We also sought input regarding the survey content from members of the coalition so that our findings would be relevant to their concerns and the data collected would be appropriate given the coalition's set of interventions.

The survey had two parts: a 19-question screener and a 67-question survey for diagnosed diabetics. It was administered in both Spanish and English. The screener covered basic questions about health status, health care utilization, insurance coverage, and health habits. The survey of diabetics asked more detailed questions about health care utilization, including experiences using the health care system, access to health care and to prescription drugs, diabetes self-management and health behaviors, diabetes-related health problems, and confidence and motivation. The survey was developed in English and then translated into Spanish by a bilingual member of the

coalition who was born and raised in Puerto Rico. A second bilingual translator of Chilean origin back-translated the instrument and established comparability of the meaning of all items in English and Spanish. The instrument was then independently reviewed by five bilingual community residents to ensure that it would be comprehensible to people with low levels of formal education and to all Spanish speakers.

The coalition subcontracted with three CBOs to field the survey: a housing development corporation that provides social services and job training and placement to its residents; a social service provider that also manages housing for senior citizens; and a social service agency that provides outreach and educational programs. Each of the CBOs was paid approximately \$5,000 to manage the recruitment of the surveyors and the supervision of the survey. These CBOs employed a total 13 community residents as surveyors (7 African Americans and 6 Latinos). Five of the surveyors were fluent in Spanish as well as English. All lived within the four target ZIP codes for the survey, with the exception of one person who lived in an adjacent ZIP code. The surveyors were paid on a per-survey basis beginning at \$15 and later increasing to \$20 per diabetes survey and \$3 per screener.

To ensure the standardization of fielding across survey sites and surveyors, all surveyors participated in a 3-day training program before entering the field. We also regularly coordinated with the survey managers at the three CBOs and held a series of debriefing sessions—usually twice a month—with the surveyors.

Identifying Potential Survey Sites and Households

Because of resource constraints, we were unable to obtain a representative random sample of housing units within the ZIP code area. Block and building-level data are not available through the census, and first-hand mapping of the sampled tracts—or “blocklisting”⁷—was not feasible. We therefore relied on the networks of the partner CBOs as well as the networks of the individual surveyors to identify an “opportunity” sample of buildings to which they thought they could gain access. Both the surveyors and the CBOs were instructed to help provide access to buildings rather than to identify individuals through neighborhood civic activities or CBO-sponsored classes or events. During the bimonthly debriefing sessions with surveyors, we asked surveyors about their strategies and assignments to confirm that this approach was being implemented. In this way, the survey effort benefited from the community relationships, and skewing of the sample was minimized.

Soliciting Participants and Interviewing Respondents

At the suggestion of the CBO managers, the surveyors announced the survey ahead of time by hanging posters and distributing flyers in targeted buildings. To guarantee consistency of message, the Center for Health and Public Service Research staff produced both English and Spanish versions of the posters and flyers, which were used across all sites. A large portion of the surveyor training concerned the protocol for soliciting participants and the techniques for administering a questionnaire. Surveyors were given a training manual with step-by-step instructions, including a scripted introduction. They practiced interviewing each other in class, allowing us to confirm that they understood both the protocol and the questionnaire. We did not observe surveyors in the field first hand. Through ongoing review of completed questionnaires and candid discussions in debriefing sessions, however, we identified and addressed problems that arose. These sessions also allowed surveyors to share successful interviewing strategies, thereby “institutionalizing” good practices.

CBO managers also participated in a series of survey planning meetings and were in regular contact with researchers during fielding. Early on in the project, we detailed the role of the survey manager, which included “opening doors” for surveyors and supervising them on an ongoing basis. Through regular debriefing sessions, we were able to aid managers’ timely distribution of survey materials, collection of completed questionnaires, and compensation of surveyors.

FINDINGS

Our method for fielding the survey—employing community residents and subcontracting with CBOs to recruit and supervise the surveyors—was shaped both by our research assumptions and by the goals of the coalition. We looked to the community surveyors and CBOs to help facilitate access to neighborhood buildings and to help elicit the trust of potential respondents. The coalition also sought to use the survey process to support individual and institutional capacity building within the community and to enhance diabetes awareness and community mobilization. To what extent were these assumptions borne out and these goals achieved?

Increasing Access and Trust

Conducting a door-to-door survey in a poor, inner-city community presents multiple challenges. Gaining entry to buildings, convincing residents to open their doors, and persuading potential respondents to participate and answer questions honestly and openly are all difficult tasks in a neighborhood in which many residents have been victimized by crimes and scams, and the level of distrust runs high.

To varying degrees, our CBO partners were able to help us overcome these obstacles by providing access to apartment buildings and developments where they had relationships, for example, as social service providers or housing managers. The housing development corporation offered ready access to their properties (1,255 units). The other two CBOs had more limited connections. One managed several buildings for the elderly; the other provided services to residents in various buildings, but had no institutional relationships to draw on. Although the CBO survey managers were sometimes reluctant to reach out to other building managers or agencies to help gain access to buildings, the surveyors, on their own the initiative, were often able to use their institutional affiliations to make these connections.

Our decision to employ community residents as the surveyors was motivated in part by our belief that they would be savvy about how to reach potential respondents and able to use their personal connections to pave the way for the survey. This proved to be true on many occasions. One surveyor used his role as a deacon in his church to inform the community about the survey effort. Another persuaded the supervisor of a senior citizens’ housing facility to distribute flyers. One of the surveyors was very thoughtful and systematic in his approach. Before beginning, he would distribute flyers throughout the targeted building. When he rang a doorbell, he would hold the flyers in one hand, the surveys in the other, and his surveyor identification card in his mouth. He was concerned that, as a relatively young African American man, he might be seen as threatening, and he consciously developed this approach to allay respondents’ fears.

We also hypothesized that respondents would be more likely to trust fellow residents and therefore be more likely to provide honest and open answers to the more sensitive survey questions, for example, those concerning barriers to access and personal experiences using the health care system. Based on our earlier focus groups

with residents from this community, we expected respondents to complain of mistreatment and barriers to access, such as long waiting times and other logistical and financial obstacles. (Because the same CBOs that managed the survey also recruited the members of the focus group, it is unlikely that the two sets of participants differed in terms of their relative access to services.) Yet, in our survey, only 16% of respondents reported that they “delayed or could not get care they thought they needed,” and only 7% said that they had ever “felt uncomfortable or had been treated badly in their experiences getting health care in the prior year.” These results, although on a par with other survey findings,⁸ did not comport with the perceptions of the surveyors and coalition members, who felt that the focus group findings were a more accurate reflection of community views.

As other researchers have pointed out, reconciling and integrating such differences in results is a challenge that is endemic to many community-based research efforts, which often collect data from multiple sources using multiple methodologies, thereby increasing the likelihood that findings will differ.⁹ The surveyors, who were acutely aware of community wariness about surveys or forms of any kind, were not surprised by this discrepancy. Several commented that people would be reticent to express their concerns or dissatisfaction, particularly about an issue potentially touching on race, unless they were in a setting in which they were given “permission” to do so. The focus groups, in which people directly discussed racial and ethnic disparities in health outcomes, provided such a setting, whereas a one-on-one encounter with a surveyor did not.

The problem of obtaining answers to sensitive survey questions cut both ways. Several of the surveyors reported that respondents were unwilling to answer questions about public assistance and income level. After further probing, however, we learned that it was often the surveyor, rather than the respondent, who felt uncomfortable. In many instances, these questions were left blank not because the respondent refused to answer, but because the surveyor was reluctant to ask.

Building Institutional and Individual Capacity

Theoretical and empirical work over the past two decades has documented the link between community involvement in “action” or “participatory” research and the enhancement of community knowledge, skills, and capacity.^{10–12} Researchers have demonstrated how community involvement in program development and evaluation has resulted in the strengthening of community-based consortia,¹³ the acquisition of knowledge about disease prevention and treatment, and the enhancement of skills for building coalitions, conducting research, and developing programs.^{14–20}

The coalition saw the survey not only as a mechanism for gathering information, but also—by contracting with the CBOs—as a way to provide support for existing community resources and strengthen institutional capacity. The ability of the CBOs to carry out their management tasks varied. At one end of the spectrum, the housing development corporation was able to use its employment bank infrastructure to process payments and monitor productivity. At the other end of the spectrum, one of the social service providers did not have systems in place to keep track of completed surveys and supplies or to process the payments for the surveyors.

The coalition also hoped that there might be some spillover effect, that is, that the staff or leadership of the CBOs would become interested in and knowledgeable about the survey and the coalition’s work. Although the CBO managers took a fairly hands-off approach to the survey, CBO staff and leadership did indeed

become more engaged and knowledgeable about diabetes and issues of health disparities. In the case of the housing development corporation, the survey manager hosted and attended many of the surveyors' monthly meetings, familiarizing herself with the survey and with the coalition's work. Other senior staff became involved in other aspects of the coalition's work as well. Following the completion of the fielding of the survey, the leadership of all three organizations became active in analyzing and critiquing the survey results and in designing a dissemination plan. These three organizations continue to be among the most committed and active of the coalition's members. Their participation in the survey helped to cement their membership in the coalition.

The coalition also saw the survey as a way to build individual capacity by providing community residents with short-term employment and the opportunity to enhance their skills. Through a 1-hour course on the basics of diabetes that was included as part of the surveyors' training (at their request), and by familiarizing themselves with the survey instrument and participating in monthly discussions, the surveyors learned a good deal about the causes, management, and consequences of diabetes. The surveyors also developed or enhanced their communications and organizational skills through the training and fieldwork. Given the limited supervision provided by some CBO management, the surveyors often coordinated the fieldwork themselves, and one surveyor assumed overall responsibility for returning completed surveys and relaying questions to researchers throughout the survey process. This person later joined coalition staff at a national conference on racial disparities. Another surveyor's demonstrated talent and energy led to a paid outreach position with one of the CBOs. Others gained information and skills, which they were able to use in their roles as community health advocates or as more active participants in coalition meetings and activities.

Providing Outreach and Mobilization

The Coalition also viewed the surveyors as potential emissaries who could promote diabetes awareness, provide increased visibility for the coalition's work, and reach out to people who needed help. Surveyors were instructed to distribute brochures with information about diabetes and coalition activities and to call attention to a "tear sheet," which respondents could fill in if they wished to volunteer or request information and services.

The surveyors varied in their attitudes toward this aspect of the work. For example, although the surveyors recruited by the housing development corporation were energetic and very productive, they rarely collected the tear sheets or linked respondents to the coalition's work or services. These surveyors, who were recruited through the employment bank, were primarily motivated by the opportunity to make money and the possibility of future employment through the CBO. Payment on a per-survey basis, with no separate payment for the collection of the tear sheets, may have led them to downplay this aspect of the task. The other two CBOs recruited their surveyors from the ranks of their community health advocates, who were already working for the coalition and committed to its mission. These surveyors were eager to link respondents to services and spread the word about diabetes management. They routinely collected tear sheets from residents in need of help managing their diabetes and referred these prospective clients to the coalition's community health advocates for follow-up services.

Impact of Methodology on Survey Sample and Data Collected

Our survey sample is roughly comparable to the rest of the community in terms of race and ethnicity (44% black and 51% Latino compared with 42% and 59%,

respectively, in the 2000 census).²¹ However, the rates of uninsurance in our full sample were very low compared with the citywide rates for the nonelderly black and Hispanic populations. In our sample, only 13% of the adults under age 65 years reported being uninsured, whereas 29% of nonelderly Hispanics and 28% of nonelderly blacks are uninsured in New York City.²² This may be partly because our partner CBOs provide outreach and Medicaid enrollment services to their residents and clients. Our sample is also skewed toward older residents, reflecting the role of one of the CBOs in serving this population and the preference of several of the surveyors for surveying in buildings that housed a predominantly elderly population.

Our survey sample was also determined by the comfort levels of the community surveyors, who were free to choose which buildings they would enter within the targeted ZIP codes. From the perspective of the surveyors, some large apartment buildings were forbidding and dangerous. It is certainly possible that people residing in those buildings differ from those in the survey sample, for example, by having less access to goods and services or being more socially isolated.

Our original goal was to collect 500 surveys from diabetics living in the target area. Several months into the fielding of the survey, we lowered our sights to about half that number. Although the surveyors drew on their own experiences and relationships to gain entry and bolster participation, productivity was very low, with the average surveyor completing only about 4 diabetes surveys and 13 screeners per month. This was true for a number of reasons. First, reflecting the high rates of illness within the community, several of the surveyors had significant health problems (including diabetes) that made it difficult for them to carry out the survey, particularly during the winter months and in the evening, when more respondents seemed to be available. In addition, with our encouragement, for safety reasons many of the surveyors went in teams of two. Each surveyor, therefore, produced fewer completed instruments. We also lost several of the younger, more energetic surveyors when longer-term job opportunities arose through the employment bank. Finally, the surveyors who were already participating in the coalition's work as community health advocates tended to focus on outreach and service delivery, often to the detriment of their data collection efforts, and it was sometimes difficult to convince them that the survey was a separate and equally important part of their work. Although we tried to increase productivity by adding a system of bonuses and prizes to our per-survey payments, many of the surveyors completed only a handful of surveys per week.

Our use of community residents as surveyors also affected the kinds of data we were able to collect, both positively and negatively. The surveyors made important contributions to the development of the survey instrument based on their familiarity with the community. For example, at the strong recommendation of the group, we deleted a question that asked for the number of people residing in the home. Many felt that this question would not be answered, or would not be answered honestly, because often more people occupy an apartment than is allowed by the lease. Particularly because many of the surveys were done under the auspices or with the sponsorship of the landlord or housing manager, the surveyors were concerned that this question would create suspicion and ill will and might lead people to refuse to participate or to withdraw from the process.

Employing surveyors from this community also meant that many had low levels of formal education. Through the role-playing and piloting of the survey that we did as part of the training process, we learned that the original instrument was too

complex, and that we needed to simplify some of the skip patterns, questions, and answer options. Although this simplification was probably useful for the respondents as well, in some cases it resulted in a lack of comparability to other survey findings. In addition, the surveyors' low educational levels may have made it difficult for them to record answers to open-ended questions readily. (The per-survey payment method may also have provided a disincentive for asking these more time-consuming questions.) As a result, for most of the sample, we were unsuccessful in obtaining useful answers to open-ended questions.

DISCUSSION

All of our work with the Bronx Health REACH Coalition has been guided by the principles of community-based participatory research.²³⁻²⁶ At each stage, we have worked collaboratively with the community residents and organizations that are members of the coalition to help shape the research agenda, select the methods to be used, implement the project, interpret and disseminate results, and determine next steps. In every instance, this process has given clarity and direction to the work and helped link research to action. Our goal has been to benefit from and build on the strengths and resources existing in this community, including the networks of individual and organizational relationships and individual skills and talents.

Our method for fielding the survey—subcontracting with CBOs to recruit and supervise community surveyors—provided us with access to potential respondents, who might otherwise have been hard to reach and supported the coalition's goals of capacity building and increasing diabetes awareness. The CBOs recruited a talented group of surveyors and were often able to open doors to buildings where they had an institutional relationship.

The CBOs were weak in their lack of management infrastructure, which made it difficult for them to supervise day-to-day operations. The coalition's subcontracts with the CBOs provided sufficient resources to buy a portion of a manager's time, but not enough to create capacity if no such person existed or if the assigned person was already overextended. Some of the bias in our sample could have been avoided if the CBOs had had the resources and capacity to reach out beyond their service populations and link with other organizations in the community. For example, the CBO partner that works with senior citizens is well known and well respected in the community. With added time and attention from that organization's senior staff, they could readily have made contact with a wide range of groups and landlords. Similarly, the presence of a full-time supervisor in the field would have helped identify safety concerns in real time and allowed appropriate assignments of survey teams and supports. Even with these resource limitations, however, the CBOs' participation in the survey effort helped to link the organizations more closely to the coalition and its mission and resulted in some spillover of knowledge and engagement of the staff.

Community residents also brought great strengths as surveyors. They were thoughtful in critiquing the survey instrument and showed creativity in gaining entry to buildings and psychological insight in eliciting the trust of potential respondents. Their discomfort or difficulty with certain survey questions and the low levels of productivity for some of the surveyors could have been remedied by more supervision throughout the process. Many of the surveyors enhanced their knowledge and skills in ways that have since benefited them or the coalition directly.

More by luck than by planning, the coalition has been able to provide other, continuing opportunities for many of the surveyors as community health advocates and coalition members, thereby continuing to build their capacity and allowing the coalition and the community to benefit from their strengths and knowledge.

Although resource constraints greatly limited our ability to obtain the kind of scientific survey sample we would have preferred, the coalition gained valuable insights into the problems faced by many of the people it seeks to serve and a deeper understanding of their knowledge, attitudes, beliefs, and behaviors. The participating CBOs continue to be deeply engaged in the coalition's work, and many of the surveyors remain active and have taken leadership roles in the coalition.

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