

Effective Recruitment of Minority Populations Through Community-Led Strategies

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Background: Traditional research approaches frequently fail to yield representative numbers of people of color in research. Community-based participatory research (CBPR) may be an important strategy for partnering with and reaching populations that bear a greater burden of illness but have been historically difficult to engage. The Community Action Board, consisting of 20 East Harlem residents, leaders, and advocates, used CBPR to compare the effectiveness of various strategies in recruiting and enrolling adults with prediabetes into a peer-led, diabetes prevention intervention.

Methods: The board created five recruitment strategies: recruiting through clinicians; recruiting at large public events such as farmers markets; organizing special local recruitment events; recruiting at local organizations; and recruiting through a partner-led approach, in which community partners developed and managed the recruitment efforts at their sites.

Results: In 3 months, 555 local adults were approached; 249 were appropriate candidates for further evaluation (overweight, nonpregnant, East Harlem residents without known diabetes); 179 consented and returned in a fasting state for 1/2 day of prediabetes testing; 99 had prediabetes and enrolled in a pilot randomized trial. The partner-led approach was highly successful, recruiting 68% of those enrolled. This strategy was also the most efficient; 34% of those approached through partners were ultimately enrolled, versus 0%–17% enrolled through the other four strategies. Participants were predominantly low-income, uninsured, undereducated, Spanish-speaking women.

Conclusions: This CBPR approach highlights the value of partner-led recruitment to identify, reach out to, and motivate a vulnerable population into participation in research, using techniques that may be unfamiliar to researchers but are nevertheless rigorous and effective. (Am J Prev Med 2009;37(6S1):S195–S200) © 2009 American Journal of Preventive Medicine

Introduction

Populations that bear the greatest burden from chronic illnesses have historically been the least represented and most difficult to engage in research.^{1–3} The good intentions of researchers and their desire to eliminate the health disparities that disproportionately affect people of color have not been enough to garner support and collaboration in activities designed to seek solutions to address this issue.

Diabetes rates are escalating across the U.S.⁴ Lifestyle change is the most effective strategy to mitigate this increase and has been shown to eliminate racial and

ethnic disparities in diabetes incidence.^{5–8} Unfortunately, interventions have not been sustained even at the very institutions that demonstrated their efficacy. The failure to translate such research into routine practice is particularly problematic for the minority communities hardest hit by diabetes and its devastating consequences.

Developing practical, sustainable programs that prevent or delay diabetes requires substantial participation of people of color in research. The barriers to their participation include distrust of researchers and research; fear among undocumented immigrants that participation might lead to deportation; and beliefs about health and illness that may cause some individuals to question the value of research.⁹ In addition, people from minority groups may not be well informed of, or appropriately invited to enroll in research programs.^{10,11} Lack of participation may also be fueled by the transient nature of research. Successful interventions often disappear with the cessation of funding used to document their effectiveness. As a result, people of

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color may view researchers as interested primarily in data collection to advance their careers; trying to portray their communities in an unfavorable light rather than to address community health problems; and lacking in commitment to give back to the community.²

The CBPR approach may address the barriers for reaching and partnering with populations that bear a greater burden of illness but have been historically difficult to engage.¹² The East Harlem Partnership for Diabetes Prevention, a community–academic partnership, employed CBPR to design and implement a pilot intervention to reduce diabetes among adults in East Harlem. Also known as El Barrio, East Harlem is the northeast corner of Manhattan. Its residents, 50% of whom are Latino and 40% black, are predominantly low-income, have among the highest obesity and diabetes prevalences, and have the very highest diabetes mortality rate in New York City.^{13–15}

The partnership's Community Action Board, consisting of 20 local residents, activists, and leaders (15 of whom live in East Harlem), was formed in 2005 to write a grant to address health disparities. The partnership (between the community and academia) conducted community assessments, chose to focus on diabetes, narrowed the focus to prevention, and built a pilot diabetes prevention intervention. As part of the trial, the board chose to develop and test the effectiveness of five community-led recruitment strategies to attract local residents, rigorously test them for prediabetes, and for those who were eligible, enroll them into a community-based, peer-led, diabetes prevention RCT. This article describes the effectiveness of these recruitment and enrollment strategies.

Methods

In keeping with CBPR principles, board members chose all strategies, codeveloped the intervention and its evaluation, and directed the researchers to provide the tools, support, expertise, and staffing necessary to meet study goals.¹⁶ To start the five-phase study, the partnership needed to find people with prediabetes-range glucose levels. Partners identified adults who were overweight (BMI ≥ 25) and obtained informed consent, so that these individuals could return after an overnight fast to determine if they had prediabetes. Returning individuals underwent 1/2 day of testing, including an oral glucose tolerance test and a survey. Eligible people (with prediabetes) had fasting finger-stick glucose levels of 100–125 mg/dL or postprandial glucose levels of 140–199 mg/dL.¹⁷ This group also had measures taken of hemoglobin A1c (average glucose), lipids, blood pressure, and waist circumference. The board, interested in maximizing the information gained from the study, asked participants to bank an additional tube of blood for future studies about prediabetes. Basic scientists interested in accessing these samples would need to formally present their ideas to the board, which would review and approve or deny the requests.

People with prediabetes were randomized to intervention versus delayed intervention in 1 year.

The partnership accomplished most of its work through subcommittees. The board's intervention subcommittee developed an 8-session peer-led program, tailored from a chronic disease self-management program, to focus on lifestyle change.¹⁸ The goal was 5%–7% weight loss, the amount shown to prevent or delay diabetes in large randomized trials.^{5–8,19} Classes were offered in English or Spanish at community locations such as churches and senior centers. The Latino education subcommittee independently developed or reviewed all study materials and the intervention to ensure they were linguistically and culturally appropriate for the Latinos from North, Central, and South America, and from the Caribbean, that live in East Harlem.

The community engagement subcommittee was charged with developing a sensitive, culturally appropriate, noncoercive recruitment and enrollment process. The goals were to create an atmosphere of inclusion and a feeling of importance from taking part; address common barriers to enrolling minority people in research; provide education about prediabetes; and explain the results of the screening. Based on a literature review and local knowledge and experiences, the subcommittee developed a Spanish/English training manual and offered a 2-day, hands-on training for all staff and community representatives participating in the project.

Training included information about maintaining confidentiality; mock interviews; and suggestions for addressing participants' resistance, including fear of experimentation, mistrust of the medical system, claiming to be too busy, and misunderstanding the research protocol.^{20–25} Staff provided verbal and written assurance that the research team would use no experimental drugs, and that personal health data would be kept confidential. The staff also stressed that the participants' primary clinicians, if applicable, would remain in charge of their care. Leaders held weekly meetings to discuss recruitment progress, highlight successful techniques, and brainstorm ways to handle difficult situations that had arisen. All people screened \$50 gift certificates to local stores; study gifts such as T-shirts and pens; and a healthy box lunch. The partnership sponsored numerous screening events at various community locations, including on weekends.

The community engagement subcommittee also developed five strategies to recruit and enroll participants in the diabetes prevention trial. The first was clinician referral, which required educating local clinicians about prediabetes. The clinician subcommittee created a toolkit, including a laminated pocket reference, information about prediabetes and the study, and referral cards so clinicians could easily refer patients. They distributed the kit to all internal medicine clinicians (physicians and nurse practitioners) practicing in East Harlem and followed up with each through phone calls, visits, and educational sessions. The second strategy was to hold board-sponsored recruitment special events, such as Stop Diabetes Day, advertised in local newspapers, flyers, e-mail blasts, and at local businesses and housing developments. These events included live music, dancing, healthy foods, and giveaways specifically tailored to identifying potential enrollees. The third approach was to present information about prediabetes and diabetes prevention to local community-based organizations (CBOs) and garner their support in

Table 1. Recruitment and enrollment results

	Total approached (n)	Total who consented and were tested for prediabetes (n)	Total screened of those approached (%)	Total enrolled (n)	Total enrolled of those approached (%)
Total Strategy	555	178	32	99	18
Clinician referral	0	0	0	0	0
Special events	46	9	20	8	17
Community organizations	106	17	16	10	9
Public events	201	27	13	13	6
Partner-led	201	125	62	68	34

approaching their clients about the study. Fourth, partners recruited participants at public events such as health fairs, street fairs, and farmer’s markets. Partners set up tables with banners and giveaways, and community members acting as greeters encouraged their neighbors to learn about the project. Finally, the subcommittee developed a community partner–led recruitment strategy. Community advocates spearheaded these efforts and detailed a strategy for how to make recruitment work at their organizations. They explained and championed the study to their own constituents and invited researchers into the process once people understood the study and showed interest in taking part. They also told the research staff what would be needed to make recruitment work, including appropriate timing of events, staffing, refreshments, and incentives, and they taught research staff how to interact with clients.

Study personnel were trained to collect data about the number of people approached through each strategy; the number who consented and returned for prediabetes testing; and the number who had prediabetes and were enrolled in the trial. During recruitment events, each potential study participant would visit a welcome desk, where partners or staff captured the data on the number of potential enrollees who had been approached and who had declined further participation before they could be screened for eligibility. At that point, staff used a computerized data management system to collect data on the flow of each person through the study. All people approached for the study received a gift after this information was obtained. The study analyst used chi-square statistics to determine the most effective enrollment strategy and differences between those enrolled and the overall East Harlem population.

Results

Between April and July 2007, partners implemented the five recruitment strategies to identify and enroll community residents with prediabetes. This included mailing the clinician education and study referral toolkit, and following up with all 295 general adult medical clinicians in East Harlem: 118 hospital or clinic-based providers, 143 residents, 8 nurse practitioners, and 26 private local physicians.

Partners approached 555 people through the five strategies, of whom 249 (45%) were appropriate candidates to be screened for prediabetes and the study (adults aged 18 years, East Harlem residents, BMI

25, English- or Spanish-speaking, not pregnant or on hypoglycemic medications). The other 306 people were ineligible (281) or declined to take part (25). The 249 who were candidates signed an IRB-approved consent to return fasting for prediabetes testing. Most of those who consented (178/249, or 71%) did return for testing. Of these 178 tested, 99 (56%) had prediabetes and were enrolled in Project HEED (Help Educate to Eliminate Diabetes). No person with prediabetes-range glucoses refused enrollment.

Three aspects of the success of recruitment efforts were evaluated: volume (number of people approached); efficiency (number enrolled of those approached); and representativeness of the community they came from (Table 1). In terms of volume, partners approached 36% of people via community partner–led approaches (201/555), 36% via public events such as health fairs (201/555), and 19% through CBOs (106/555) (Figure 1). Only 8% (46/555) were approached through specially produced events. Clinicians referred no participants to the study. Partners tested more participants for prediabetes through the partner-led strategy (implemented at one family service agency and two churches) than with the other approach. Fully 62% (125/178) of those approached using the partner strategy returned

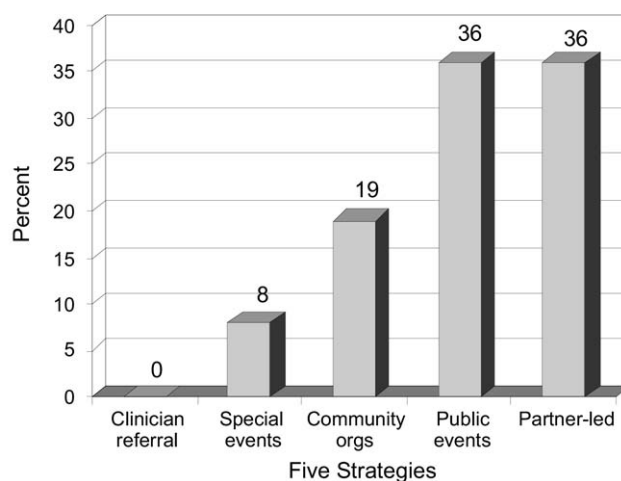


Figure 1. Adults approached through the five strategies (n = 555)

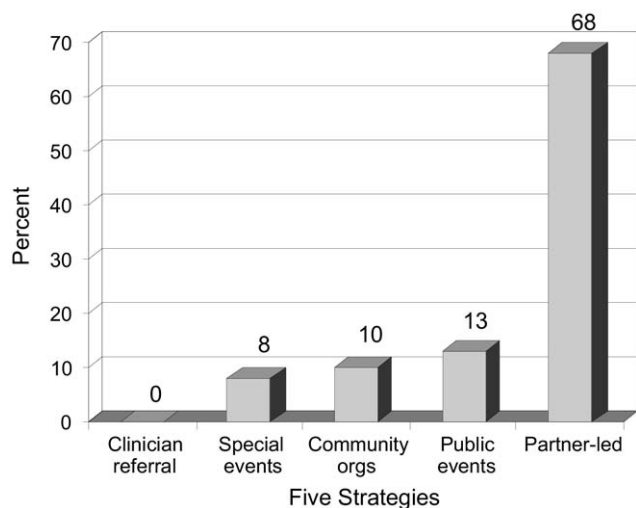


Figure 2. Adults enrolled through the five strategies (*n* = 99)

for prediabetes testing, versus 20% for the other four approaches (*p* = 0.01; Table 1).

Partner-led strategies were the most efficient form of recruiting those who were ultimately eligible and enrolled (Figure 2). More than two thirds of the 99 adults enrolled were identified using the partner strategy, versus 0%–13% for the other strategies (*p* = 0.01). And, fully 34% of those approached through partner-led strategies were eligible and enrolled, versus 0%–17% using any of the other four strategies (*p* = 0.0001).

Regarding the representativeness of those enrolled, Table 2 reveals that the population enrolled was generally low-income, uninsured, undereducated, unemployed, and non-English speaking. Enrollees were 89% Latino, 9% black, 1% Asian, and 1% Native American; 25% were food insufficient (those who skip meals or do not eat enough because of lack of money). Only 11% reported their health as very good or excellent, and 50% reported depressive symptoms. Compared to the overall East Harlem population, in the enrolled group there were significantly more women, Latinas, and unemployed, uninsured, and obese people. Those enrolled had poorer self-reported health, although they had similar education attainment and yearly income.

Discussion

Using the CBPR approach, partners evaluated the effectiveness of various recruitment and enrollment strategies. This was a demanding recruitment. Participants were asked to come twice, once to be prescreened and once to return, after an overnight fast, for prediabetes testing, to drink an oral glucose solution, stay for nearly 1/2 day of testing, and have repeated finger-sticks and blood draws. Yet in just 3 months, partners were able to recruit and enroll 99 people from a vulnerable cohort that many would consider quite challenging to reach and engage in research. Clinician referrals, a commonly

used recruitment strategy,³² yielded no participants. In contrast, a community partner-driven strategy approached, screened, and enrolled the largest proportion of participants in this trial.

While partner-based strategies resulted in a high volume of people enrolled in an efficient manner and in a relatively short time, this population was not truly representative of East Harlem. Most participants were Latina, as the first organizations the board partnered with served mainly this ethnic group. The planned pilot sample size was reached so quickly in working with these organizations that the community action board did not go further. In addition, the board aimed to engage people who were often under-represented in research, including non-English speaking, low-income, uninsured, under-educated people, and it sought out organizations with connections to these groups. As a measure of this success, these individuals may have been over-represented in the study.

Many approaches have been cited as effective in recruiting and retaining people of color in research, including the use of culturally tailored, community-based approaches. These include collaborating with community partners and community boards to develop recruitment materials, conduct outreach, build trust and rapport, include flexibility in schedules, and work with

Table 2. Characteristics of enrolled participants and the East Harlem population

	Enrolled (<i>n</i> = 99)	East Harlem residents (<i>n</i> = 108,000)	<i>p</i> -value
Age (M, SD)	48 (16.5)	NA	
Women (%)	85	53	0.0001
African-American (%)	9	33	0.0001
Latino (%)	89	55	0.0001
Mexican	54		
Puerto Rican	24		
Ecuadorian	11		
Dominican	9		
Other	2		
Spanish-speaking only (%)	77	NA	
Education (%)			
Did not complete junior high school	25	21	0.3226
Did not complete high school	58	56	0.7626
Not working (%)	70	52	0.0004
Yearly household income <\$15,000 (%)	45	38	0.1466
Uninsured (%)	49	11	0.0001
Food insufficient (%)	25	NA	
Self-rated health as fair or poor	68	30	0.0001
BMI (%)			0.0264
Overweight (BMI 25.0 to 29.9)	38	31	
Obese (BMI ≥ 30)	62	31	

NA, not applicable

gatekeepers—individuals trusted and sought after for advice by residents.^{1-3,20,26-36} Yet partners found no references to researchers relinquishing control of community-based recruitment. For the current study, allowing community partners to lead the recruitment efforts facilitated identification of potential subjects who were ultimately both eligible *and* enrolled in an intervention with sufficient relevance that community members were enthusiastic, rather than reluctant, participants.

In analyzing these data during a board retreat, community leaders attributed this success to the commitment of both community and academic partners to each other and to the research. Although this commit-

ment required adherence to a tight timeline and rigorous methods, it also ensured that the project resonate with and provide direct benefit to the community. Community partners understood and advocated for local needs and approaches and insisted clients' needs be met as a condition of their participation. Their longstanding, trusting relationships and history of service likely broke down barriers to participation and engendered trust in the project via their dual role as research partners and advocates. The partnership developed an evidence-based intervention the community actually *wanted*, and that was created for and by members who knew the community well.

The road was not always smooth. For example, outreach workers at one partner site became frustrated that researchers were too rigid and were not fully including the workers' recommendations in recruitment efforts. Instead of leaving the partnership, their relationship with researchers prompted them to negotiate a way to restructure the protocol that did not compromise research integrity. Partnering with organizations that work at a grass-roots level may be optimal when recruiting in communities of color. Lessons learned will inform next steps, as partners begin a larger randomized trial to prevent or delay diabetes. The board has committed to continuing to create alliances that facilitate this approach.

Success must be balanced with limitations. This was a small study conducted at relatively few sites in one urban community. Further, it was not possible to randomize people to the five strategies, and this may have led to selection bias. People more amenable to research may have been more amenable to joining or receiving services from organizations that have strong, trusted leaders (i.e., those who ran partner-led recruitment for the pilot). These sites may be more cohesive and include people who are "joiners" by nature.

However, there may be similar pitfalls for those recruited through highly standardized clinical trials. For example, the Diabetes Prevention Program required people to come to several visits and keep detailed food diaries before enrolling, which may select for more literate people with better support to enable such intensive participation, and appeal to more moti-

vated individuals.⁵ Thus, CBPR may engage populations that are not drawn to more clinically based programs, but are still inspired to take action to improve their health. Future research should determine if this approach will be effective with more-diverse populations and in more-diverse settings. Nevertheless, this approach holds great promise for recruiting vulnerable and hard-to-reach populations. The team aims to continue recognizing and directly addressing the tensions between community and academic priorities that, instead of becoming barriers to working constructively, serve as critical elements in effective recruitment and act as the glue that holds partnerships together.

We thank all members of the Community Action Board for their immense contributions; the community partners and organizations who work with us; and Crispin Goytia, Carlton Bailey, Anika Martin, Carlo Canepa, Ken Fernandez, Donna Bonn, Jose Moreno, and Judit Dieguez for their outreach and recruitment efforts.

This work was supported by grant number 5R24MD001691-03 from The National Center on Minority Health and Health Disparities and the Diabetes Prevention and Control Program of the New York State Department of Health.

No financial disclosures were reported by the authors of this paper.

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