



Case Study: Project HEED



Principal Investigator

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Project

Project HEED (Help Educate to Eliminate Diabetes) was developed based on a National Institute on Minority Health and Health Disparities request for proposals that asked researchers to develop a pilot project using a community-based, participatory research model.

The researchers actively engaged the people who they were trying to reach. For example, the researchers convened a board of about 20 community members who not only represented different facets of the community, including churches, senior centers, and public safety, but also exemplified diversity in gender, race, ethnicity, and socioeconomic status. For participating in the project, the community board members received stipends and other benefits, such as food at their meetings. The board was

invested in the project from the beginning and helped develop the recruitment strategy.

The community picked diabetes prevention as the research focus. The study tested an intervention for diabetes prevention: an 8-week, peer-led educational workshop to inform people about diabetes and empower them to make lifestyle changes. During the pilot study, the group that received the intervention lost more weight and was more likely to maintain the weight loss for 1 year than the group that did not receive the intervention.¹

The study was followed by a dissemination phase. The research team held focus groups to find out what the study participants thought would help them sustain their progress in the long-term. The focus group findings led to the development of an app that combines diabetes education with community organizing to help users understand and address the community factors that lead to unhealthy eating, lack of physical activity, obesity, and diabetes.

Target Population

The study focused on low-income women in East Harlem with a body mass index (BMI) greater than 25 who did not think they had diabetes or prediabetes. Many were Spanish-speaking Latina women and African-American women.



1. Parikh, P., Simon, E. P., Fei, K., Looker, H., Goytia, C., & Horowitz, C.R. (2010). Results of a pilot diabetes prevention intervention in East Harlem, New York City: Project HEED. *American Journal of Public Health*, 1 (Suppl 1), S232-S239. PMID: [20147680](https://pubmed.ncbi.nlm.nih.gov/20147680/).

Recruitment Approach

The researchers worked closely with the community board on recruitment strategies for the study. Through regular board meetings, the community group developed trust and worked with the researchers on devising a recruitment strategy. The group acquainted the researchers with the community and its challenges. The academic team was transparent about timeline and budget, explaining to the board members that the trial needed to occur within a certain amount of time to enable the researchers to compete for another 5 years of funding.

Recruitment sites included food pantries, senior centers, social clubs, Parent-Teacher Association meetings, and preschools.

The researchers used five recruitment strategies in the pilot study:

- Through clinicians
- At events such as farmers markets
- At special recruitment events
- At local organizations
- By empowering partners to recruit at their sites



Primary Barriers

Barriers to participation for women in the targeted study population included the following:



Language. Many of the women only spoke Spanish or had low-literacy skills in English.



Time. Potential participants had to engage in a multipart consent and enrollment process. After the researchers determined eligibility, the women had to go through the consent process and then undergo a blood sugar test while fasting. Many of these women had to care for family members and had limited free time.



Location. Many of the women lacked transportation.



Incorrect assumption of non-eligibility. Some of the women did not think that the research was meant for them.



Distrust. Some of the women distrusted authority related to immigration status.

Successful Recruitment Strategies

- Of the recruitment strategies listed earlier under “Recruitment Approach,” the most successful strategy was empowering community partners to recruit participants.² For example, one organization that worked with largely undocumented, non-English-speaking women, who historically are a very difficult group to engage in research, soon had a waiting list for the study.
- Recruitment materials were developed with the low-income female audience in mind. Subcommittees reviewed the materials to ensure that they were linguistically and culturally appropriate. The Mount Sinai Institutional Review Board (IRB) helped the researchers revise the legal language used in the consent forms to make it more understandable to the study participants. The experience even influenced the IRB’s approach to other studies with low-literacy populations.

2. Horowitz, C. R., Brenner, B. L., Lachapelle, S., Amara, D. A., & Arniella. (2009). Effective recruitment of minority populations through community-led strategies. *American Journal of Preventive Medicine*, 37(6, Suppl 1), S195-S200. PMID: [19896019](https://pubmed.ncbi.nlm.nih.gov/19896019/).

- Joining the study took several hours and required participants to be measured for BMI and undergo intake tests. For convenience, the researchers held the recruitment events on the weekends and hosted them at community sites that provided a play area for the participants' children. Upon joining the study, the participants received a gift to welcome them to the team.
- The community board said that a randomization in which some people did not get the intervention was unacceptable. Consequently, study participants who were randomized into the control group were eligible for the intervention after a delay of 1 year. Pregnant women were excluded, because the study tested a weight loss intervention; however, they were invited to participate after giving birth.

Retention Strategies

- The intervention and follow-up measures were held in community settings, in places and at times that were convenient for participants. Events were structured to be pleasant and comfortable.
- Because the researchers were testing the intervention for effectiveness in a real-world setting, the study did not provide child care, transportation, or compensation for participation in the intervention. The community board made the decision to not provide ongoing incentives for participation, because they wanted to design an intervention that was sustainable by the community. Instead, they focused on scheduling the educational sessions at locations and times that were most convenient for participants.
- The researchers sent the participants birthday cards and study anniversary cards as well as occasionally called them on the phone.

Lessons Learned

- The academic side of the team occasionally offended a community member by implying a lack of trust in their

work. For example, the academic team repeated height and weight measurements that had been taken in an initial screening, thereby offending the community team; the academic team could have avoided this offense by explaining more thoroughly why they needed to retake the measurements or by making it possible for the initial screener to take more accurate measurements.

- The most effective recruitment strategy was empowering community organizations to recruit people.
- Reaching enrollment targets is usually an extremely difficult part of carrying out a trial, but the community-based participatory research model made it easy.

“We eat together, we laugh together. They know my kids’ names. I know their kids’ names. It’s like a research family and that social trusting environment where we have retreats, where we have holiday parties, where we send birthday cards. That’s part of what builds something where it’s fun.”

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