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## Experiences and Lessons Learned in Using Community-Based Participatory Research to Recruit Asian American Immigrant Research Participants

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### Abstract

**Purpose**—By 2050, the number of international migrants is expected to double from 214 million people. Of these, Asian immigrants are projected to comprise the largest foreign-born population in the United States by the year 2065. Asian American immigrants experience numerous health disparities, but remain under-represented in health research. The purpose of this article is to examine the experiences and lessons learned in applying community-based participatory research (CBPR) principles to access and recruit a sample of Asian American research participants.

**Approach**—This article reviews unique barriers to research participation among Asian Americans, describes the principles of CBPR, and provides examples of how these principles were employed to bridge recruitment challenges within a qualitative study.

**Findings and Conclusions**—CBPR facilitated greater research participation among a group of immigrant Asian Americans. Researchers must be additionally mindful of the importance of building trusting relationships with their community partners, understanding the significance of shared experiences, considering fears around immigration status, and considering ongoing challenges in identifying and reaching hidden populations.

**Clinical Relevance**—Clinicians and researchers can employ CBPR principles to guide their work with Asian immigrant communities and other under-represented groups to facilitate access to the population, improve participant recruitment, and foster engagement and collaboration.

### Keywords

Asian American; community-based participatory research; immigrants; recruitment

Community based participatory research (CBPR) is a collaborative, action-oriented research approach that seeks to address health disparities through aligning community members' insider knowledge of their communities with academic researchers' methodological expertise (Minkler, 2005; Wallerstein & Duran, 2010). CBPR draws on critical and social theory to promote equal partnership and decision making. This collaboration minimizes the hierarchy traditionally found in research (Minkler & Wallerstein, 2003). The CBPR approach is applicable to many health conditions in a variety of contexts, and has been primarily employed with low-income groups and communities of color (Israel et al., 2010). Core values of this approach include partnership and collaboration between communities and researchers, equitable power distribution, trust and mutual commitment, and an openness to knowledge acquired from participants' experiences (Israel, Schulz, Parker, & Becker, 1998). These values are the basis for collaborative research partnerships focused on alleviating complex health problems.

### Health Disparities Among Immigrant Groups

In many countries, ethnic minority immigrants are a growing segment of the population who are likely to experience health disparities (Miramontes et al., 2015; Pottie et al., 2011). Over the past 20 years, increasing numbers of migrants from middle-income countries in Asia, Latin America, and Eastern Europe have settled in high-income countries such as the United States, Australia, Great Britain, and Canada (Connor, Cohn, & Gonzalez-Barrera, 2013). As an example, by 2050, the population in the United States—which is the world's top immigration destination—is expected to grow from 320 million to 458 million people (U.S. Census Bureau, 2015), of which 136 million will be immigrants (Ortman & Guarneri, 2010). Similarly, Germany, which ranks second in terms of migrant-receiving countries (Organisation for Economic Co-operation and Development, 2015), is presently experiencing a large and sudden migration wave as a result of the Syrian refugee crisis. A recent analysis of global migration trends notes that African migrants from sub-Saharan Africa move primarily within Africa; the biggest migration flows from West Africa are to Western Europe; Latin Americans move predominantly to North America and Europe; while South Asians and South-East Asians migrate to Western Asia, North America, and less frequently to Europe (Abel & Sander, 2014). These migration trends highlight the fluid changes occurring in host countries. Furthermore, they underscore the salience of broadly understanding CBPR and how it may be employed to better understand the health needs of ethnic minorities to better develop “migrant-sensitive health systems” (World Health Organization, 2010, p. 4).

Immigrants are a subset of the ethnic minority population with myriad health risks and health needs that are poorly understood. For example, Asians represent the fastest growing proportion of newcomers to the United States (Hoeffel, Rstogi, Kim, & Shahid, 2012). Composed of more than 14 subgroups, they are tremendously diverse in geographic origin, language, religious affiliation, immigration status, and cultural beliefs and practices (Tseng, 2009). Historically, Asian Americans have been under-represented in health research, and many studies that do include Asian Americans present aggregated data, masking critical health differences between ethnic subgroups. Disaggregated data demonstrate health

disparities among subgroups on a number of chronic conditions, including cancer, heart disease, and mental health problems (Nadimpalli & Hutchinson, 2012). Factors contributing to deleterious health outcomes include limited health literacy, cultural and linguistic factors, and perceived discrimination (Clough, Lee, & Chae, 2013; Harris, 2012; Kandula, Kersey, & Lurie, 2004). Failure to address these factors presents tremendous costs on an already strained healthcare system. Greater research participation among Asian American immigrants is critical in order to better understand their health needs and disparities and effective tailored interventions.

### **Difficulties Recruiting Ethnic Minority Research Participants**

Researchers have historically encountered challenges to accessing and recruiting those from under-represented groups. Individual participant-, investigator-, and system-level barriers may contribute to a lack of research participation among ethnic minorities. Participant-level individual factors include lack of time, transportation, linguistic mismatching, fear and mistrust of research, and lack of awareness of participating in research (Han, Kang, Kim, Ryu, & Kim, 2007; Hsu, O'Connor, & Lee, 2013). Investigator-level barriers include poor communication about health research across various phases of the research (George, Duran, & Norris, 2014); the erroneous application to ethnic minorities of recruitment strategies that have been successful with White research participants (Banda, Germain, McCaskill-Stevens, Ford, & Swain, 2012; Hussain-Gambles, Atkin, & Leese, 2004; UyBico, Pavel, & Gross, 2007); and a poor understanding of cultural differences among ethnic minority groups (Sheikh et al., 2009). Finally, system-level barriers include institutionalized racism and discrimination (George et al., 2014); a lack of ethnically diverse researchers (Byrd et al., 2011); and research study design and implementation that is incongruent with community values (Robinson & Trochim, 2007).

### **Difficulties Recruiting Asian Immigrant Research Participants**

A brief literature review highlights specific difficulties in recruiting and retaining immigrants into research studies. Decreased access to and knowledge about research is a recognized barrier to research participation among immigrants (Chen, Kramer, Chen, & Chung, 2005; Harrigan et al., 2014). Linguistic mismatches may alienate English-speaking researchers from research participants with limited English proficiency (Chang et al., 2014; Chen et al., 2005; Shedlin, Decena, Mangadu, & Martinez, 2011). Similarly, competing responsibilities with work and child or elder care take precedence over research study participation, which poses additional constraints on time, lost wages, and transportation difficulties (Chen et al., 2005; Ganann, 2013; Han et al., 2007; Loue & Sajatovic, 2008).

An unfamiliarity and distrust of the research process may limit Asian immigrants' research participation. In addition, skepticism with the trustworthiness of institutions such as universities and hospitals may create distrust. Specifically, undocumented immigrants are a hidden population who may have greater difficulties trusting outsiders since their migration journeys have been difficult and expensive and they fear deportation (Shedlin et al., 2011). For these individuals, research participation and the informed consent document in particular are viewed as a threat to immigration status (Chen et al., 2005; Han et al., 2007; Loue &

Sajatovic, 2008; Shedlin et al., 2011). Monetary incentives for research participation may be negatively interpreted due to incongruence with cultural values. Chen et al. (2005) found that among the Chinese, accepting money for research participation was perceived as a degrading act, and others regarded monetary compensation as a scam, which led potential research participants to discredit the research altogether. Researchers must be mindful of the multiple views through which research is perceived. To that end, community member involvement throughout the various phases of research design and implementation are a critical component of ensuring successful participant recruitment from under-represented groups.

## Study Example

To contextualize this discussion on employing CBPR principles to access and recruit hard-to-reach populations such as Asian immigrants, this article will use as an example a recent study published by Katigbak et al. (2015). This qualitative study was conducted to explore the roles of community health workers (CHWs) in facilitating the adoption of healthy behaviors among Filipino Americans with hypertension. A subsample of interview participants ( $n = 13$ ) was recruited from among the participants enrolled in a larger intervention study, Project AsPIRE (Asian American Partnerships in Research and Empowerment; Ursua et al., 2014). The purpose of this article is to describe the experiences and lessons learned in applying CBPR principles to recruit immigrant Filipinos into this qualitative study.

## Principles of CBPR

Successful CBPR partnerships are underscored by nine guiding principles: (a) recognizing community identity; (b) building on community strengths and resources; (c) developing systems in an iterative and cyclical process; (d) developing equitable involvement of all parties in all phases of the research; (e) engaging in co-learning and capacity building; (f) establishing mutually beneficial integration and balance of research and action; (g) addressing public health issues of local importance; (h) sharing participation in the dissemination of research findings; and (i) committing to a long-term process of sustainability (Israel et al., 1998). These CBPR principles are described along with examples of how these principles guided the recruitment of immigrant Asians into a qualitative study.

### Recognizing Community Identity

The first CBPR principle refers to identifying the communities with whom researchers work, and understanding the shared values and norms that are bounded by group membership, such as geography or social networks (e.g., family or friends). With this knowledge, researchers aim to strengthen a sense of community through collective engagement among community members (Israel et al., 1998). As an example, 3 years prior to initiating the study the principal investigator (PI) began working with the AsPIRE research team as a volunteer data collector. She attended community forums, health fairs, research meetings, and trainings. At each of these events, a community member who was aware of the PI's desire to work with the community facilitated introductions to leaders and gatekeepers. Participating in these activities are consistent with Israel et al.'s (1998) principle of learning about the

communities with whom they plan to partner, and making efforts to understand the various values and beliefs that will influence the collaboration.

### **Building on Community Strengths and Resources**

A CBPR approach identifies and builds upon community strengths, resources, and relationships. By establishing collaborative networks within the community, individuals and organizations can leverage their skills and resources to improve overall health and well-being (Israel et al., 1998). In alignment with this principle, partnering with a local CBO that was highly visible and respected in the community helped the PI to establish community credibility and facilitated entrée to a number of other organizations. In addition to recruiting study participants, these networks allowed her to recruit community members who participated in the research process as advisory board members, data collectors, transcribers, and interpreters.

### **Developing Systems in an Iterative and Cyclical Process**

This includes developing and maintaining partnerships, community assessment, defining problems, developing research methods, data collection, analysis, and interpretation, disseminating research findings, taking action, and finally, developing plans for sustainability (Israel et al., 1998).

### **Developing Equitable Involvement of All Parties in All Phases of the Research Process**

Collaborative partnerships among community members and researchers involves efforts to identify the research problem, collect and interpret data, and apply the results in a manner that reflects shared decision-making power (Israel et al., 1998).

### **Engaging in Co-learning and Capacity Building**

As a dynamic learning process, CBPR facilitates opportunities for reciprocal teaching and learning for all partners. For instance, as researchers learn about community values, strengths, and health needs, community members learn new information or skills that may directly benefit the community (Israel et al., 1998).

To illustrate these three preceding points, the PI actively involved community partners in the research process, and this partnership facilitated reciprocal learning and fostered community members' research skills. Collaborating with a trusted and prominent CHW provided the PI with insider insight into the community. Researchers sought community members' input from the study's inception. Their suggestions drove many methodological decisions. For instance, poor enrollment rates early in the study prompted the research team to modify the recruitment strategy. Feedback from the CHW and community advisors led to the conclusion that CBPR-aligned recruitment methods involving in-person recruitment were more appropriate than mailed recruitment letters. Through this process, the CHW learned about hidden populations (a group of undocumented domestic workers) within the community that she would not have otherwise gained access.

Community members made critical contributions to research discussions and prompted improvements that ultimately strengthened the study, from strategizing about which

community events would result in recruitment opportunities, devising culturally appropriate interview questions, to brainstorming effective ways to present research findings. Community members not only gained exposure to the research design and implementation process, but developed their skill set in understanding and applying research principles by participating as data collectors, transcribing interviews, and preparing posters presentations.

### **Establishing Mutually Beneficial Integration and Balance of Research and Action**

The CBPR approach aims to translate research knowledge towards enacting social change (Israel et al., 1998). Thus, researchers benefit from achieving their study goals while community members see the study findings practically applied in a way that improves the community (Israel et al., 1998). Soliciting community members' perspectives on the roles of CHWs helped to reinforce their ownership over the program and highlighted its ongoing contributions to the community. Through capacity building and advocacy, the CHWs empowered community members to organize themselves towards establishing a drop-in community center that became a resource for all residents. Thus, researchers met their study objectives, and the results ultimately validate CHWs as a suitable approach to improve health outcomes for under-represented immigrants.

### **Addressing Public Health Issues of Local Importance**

CBPR addresses health issues of relevance to the community while considering the social determinants of health from a systems and ecological perspective (Israel et al., 1998). In a foundational community assessment of Filipinos in New York City, concerns emerged regarding the lack of access to affordable and culturally competent healthcare services (Abesamis-Mendoza et al., 2007). The AsPIRE CHW program was developed to respond to this need (Ursua et al., 2014). In seeking to better understand the roles of CHWs in promoting healthy behavior change, researchers further explored these community concerns. They learned that CHWs successfully bridge the divide between the community and the medical establishment, working with individuals, community service agencies, and local government to improve immigrant integration (Katigbak et al., 2015).

### **Sharing Participation in the Dissemination of Research Findings**

This principle acknowledges that information produced from the research is shared, and encourages all partners to participate as co-authors on publications and presentations (Israel et al., 1998). The PI sought feedback from study participants on her interpretations of their words prior to preparing a poster for a national presentation. In addition, the CHW who collaborated with the PI was included as an author on this poster.

### **Committing to a Long-Term Process and Sustainability**

Partners demonstrate their mutual trust, support, and investment towards a common goal (Israel et al., 1998). Academic and community partnerships established through the qualitative study are ongoing, and the study findings were used to inform the activities of current CHW interventions. In summary, these CBPR principles speak to a collectivist orientation to research that aims to build equitable, long-lasting relationships that enhance community health and well-being.

## Lessons Learned

The following lessons learned summarize four key themes for researchers to consider when undertaking CBPR work with difficult-to-reach groups, such as Asian immigrants.

### Building Relationships and Trust With Communities

Building trusting relationships with community organizations facilitated recruitment and the process of community buy-in. As an outsider seeking to gain access, the PI built a relationship with both the CBO and the academic research team conducting AsPIRE over a 3-year period. The early stages of these relationships were characterized by frequent points of contact, continuous dialogue, and demonstrating that the PI's intentions and long-range plans were aligned with both the CBO's and academic research partner's goals. Establishing these partnerships early on was critical to the PI gaining visibility as someone committed to and invested in being a part of the community. Explicitly stating what gains could be achieved through partnering enabled all parties to recognize areas of synergy moving forward.

Active outreach to participate in community activities and meeting in person conveyed an interest beyond the research project. These approaches in particular were conducive with Filipino cultural values stressing the importance of interpersonal relationships. This "upfront work" described by Shedlin et al. (2011) enabled the PI to connect with community members long before initiating the research study, and minimized potential issues of a power hierarchy between the PI and the community.

The advisory board and multiple community champions were instrumental in identifying best ways to approach the community, convey the importance of the study, and change community members' perceptions of the researcher as "other." Building relationships with researchers allowed community members to engage as equal members of a research team from shaping the study design to disseminating study findings. Researchers benefited from these relationships by learning about their community partners, establishing their credibility, visibility, and gaining added legitimacy to their proposed community work (Islam et al., 2014; Shedlin et al., 2011; Ursua et al., 2014). Strong partnerships with community champions helped to promote trust between community members and researchers. Prior to starting recruitment activities, researchers must be mindful to invest adequate time and resources in building partnerships. These relationships serve as an important informational base for culturally relevant recruitment strategies (e.g., tailored messaging, recruitment sites, and relational dynamics among community organizations and members). Similarly, this information can be further extended to identify and develop strategies for addressing potential barriers to recruitment.

### Shared Ethnicity Is Not Synonymous With Shared Experience

Working with the community highlighted the variation and heterogeneity of immigrant experiences. In planning the study, the PI believed that her shared ethnicity with participants would lead them to accept and welcome her as part of the local community. While a shared ethnicity was an asset to understanding some cultural nuances in communication and values,

the challenges faced by first-generation immigrants (with which all participants self-identified) were very different from the experiences of the PI, who is a second-generation immigrant. Issues of perceived discrimination, acculturation stress, and financial burdens were more salient for study participants than for the PI herself.

Although linguistic and ethnocultural matching between research participants and study investigators may be perceived as an ideal condition (Chang et al., 2014; Chen et al., 2005), our experience highlights that these similarities alone do not lead to trusting research relationships. Researchers' decisions are greatly shaped and influenced by their social standing (Muhammad et al., 2014). Thus, similar life experiences may be more relevant in bridging differences in social class, income, and education than shared ethnicity or language. Partnering with local community members (such as CHWs) who share these common experiences may be a way to bridge this social distance during the recruitment and data collection periods.

### **Immigration Status Is a Barrier to Study Participation**

The research team gained valuable insight into the daily context of participants' lives that complicate their ability to engage in research activities. Women in a domestic worker's support group shared that many of them were undocumented immigrants. They were fearful of the consequences that participating in research or seeking medical care would have on their immigration status and livelihood. These women had migrated to the United States on their own, often leaving spouses and children behind. They remitted large portions of their wages to dependent family members in their home country. Fears relating to the consequences of revealing their undocumented status weighed heavily on their minds. One participant shared, "I am supporting many [family members] back home [in the Philippines]. What will happen to them if I cannot work here?" (49-year-old woman, mother of 2 college-aged kids). Another participant (a single 49-year-old woman) shared that she had to be very vigilant about only allowing those who "could be trusted" to be aware of her immigration status. In particular, establishing a documentation or paper trail over which one had no control was especially distressing to a number of participants.

Most participants had no previous experiences with research. During the informed consent process, concerns emerged regarding how the informed consent document and interview data could be used beyond the scope of the described research study. Similarly, questions arose about whether the data would be used to discredit CHWs. One participant, a 52-year-old married woman, questioned the PI, stating, "You're not going to use this to fire her or something—she is a good person." These statements were surprising to the PI, since the written recruitment and informed consent materials did not allude to reporting data to individuals or organizations not directly related to the research team. These participant concerns highlighted the need for explicit reassurances about the confidentiality of the research data and clear statements that research participation would not influence one's immigration status. Nonetheless, researchers should anticipate similar concerns to arise. Future work with immigrant groups should assess for unique community issues such as these so they can be addressed with additional explanations in addition to the detailed informed consent.



## Reaching Hidden Populations Remains a Challenge

Many participants, especially those employed as live-in caregivers, shared that their free time to participate was severely limited since their work conditions were not consistent with a 9-to-5 workday. It became apparent that flexible alternatives for recruitment and data collection were necessary for this group. Community champions suggested holding interviews on weekends, or outside of normal business hours close to the participants' homes, workplaces, or places of worship, as possible strategies to increase research participation.

Participants noted that although AsPIRE was a well-received project within the community, greater work must be done to reach those who are socially isolated and less inclined to engage with community groups or organizations. These individuals who lack the social supports and resources available through group membership remain a hidden subset of the population and may have higher health risks. One participant mentioned, "There are many [who did not participate in AsPIRE] who could benefit from the program ... but they don't come out [to community events], so they don't know" (61-year-old married woman). This comment echoed the sentiment shared by other participants concerning the hardships of immigration. Migration brings growth opportunities for many, but for others it drives a profound sense of loss and displacement. These people in particular may be less integrated with the host country and could be experiencing acculturation stress. They might have little interest in health promotion activities and may be engaging in risky health behaviors that further perpetuate health disparities in this group. Thus, innovative methods for effectively reaching hidden subgroups of the population who may have increased health risks are sorely needed.

CBPR approaches may be used to effectively partner with immigrant communities in conducting research. However, recruitment facilitated through community champions and various organizations does not always ensure that vulnerable subsets of the community are reached. Similar to Shedlin and colleagues' (2011) experience in conducting research with undocumented Latino immigrants, we learned from our own participants that future studies seeking to reach hidden populations, namely those who are socially isolated, or undocumented may require more creative recruitment methods. These groups lack a sampling frame; thus, participant-driven recruitment—a form of respondent-driven sampling (Heckathorn, 2002) that is conducted within a CBPR framework—may be a suitable approach to recruiting those from under-represented groups (Tiffany, 2006). Several studies focusing on hidden groups within immigrant populations that include the undocumented, men who have sex with men, and those who are injection drug users (Brouwer et al., 2009; Montealegre, Risser, Selwyn, McCurdy, & Sabin, 2012; Rhodes & McCoy, 2015) have successfully used this sampling strategy to recruit research participants. Limitations to using a CBPR approach from a research standpoint may include the substantial time investment in establishing community partnerships as the process of relationship building may delay project start dates or meeting grant deadlines, and challenges may arise in managing large and diverse groups with multiple interests. Finally, the goals and expectations of collaborators involved in research projects may be misaligned; thus, open and transparent conversations to reach a compromise should be considered. Reaching under-represented

groups will be an ongoing challenge in addressing health inequities; however, building strong partnerships that demystify and facilitate the research process towards achieving a common goal are small steps towards improving health outcomes.

## Conclusions

The recent explosion of global migration fueled by political unrest, unstable economies, and environmental disasters are accompanied by a concomitant surge in health needs. Thus, targeted methods to access and recruit research participants from under-represented communities is sorely needed. CBPR approaches are a helpful strategy towards this end. Our experience in accessing and recruiting research study participants from immigrant communities may provide guidance to others embarking on similar work. CBPR leverages community members' knowledge and expertise to facilitate the research process. Additional hurdles, however, exist in identifying and gaining the trust of hidden subsets of the target population; cultural brokers or insiders such as CHWs may be critical allies in recruitment. Along with investing greater time and resources in conducting formative work to establish community–researcher partnerships, novel methodologies to reach hidden groups should be explored, such as peer-driven or respondent-driven sampling. Engaging community members as study recruiters who share common experiences—not just a common culture and language—is an important component that should be considered. Through these efforts to partner with immigrant communities, greater strides may be made in addressing their health needs to promote overall health and wellness.

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### Clinical Resources

- Centers for Disease Control, Immigrant and Refugee Health. <http://www.cdc.gov/immigrantrefugeehealth/>
- Evidence-based Clinical Guidelines for Immigrants and Refugees (Canadian Medical Association Journal). Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3168666/pdf/183e824.pdf>
- U.S. Committee for Refugees and Immigrants. <http://www.refugees.org/resources/for-service-providers/working-with-refugees.html>