

2017

Latinos Unidos por la Salud: The Process of Developing an Immigrant Community Research Team

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Recommended Citation

Vaughn, L. M., Jacquez, F., Zhen-Duan, J., Graham, C., Marschner, D., Peralta, J., García, H., Recino, M., Maya, M., Maya, E., Cabrera, M., & Ley, I. (2017). Latinos Unidos por la Salud: The Process of Developing an Immigrant Community Research Team. *Collaborations: A Journal of Community-Based Research and Practice*, 1 (1). Retrieved from <http://scholarlyrepository.miami.edu/collaborations/vol1/iss1/2>

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Latinos Unidos por la Salud: The Process of Developing an Immigrant Community Research Team

Abstract

The tremendous Latino growth combined with the challenges of living in a nontraditional migration area make Latinos, particularly those who are undocumented, a “difficult-to-reach” and understudied population in research. We describe the development and practice of an immigrant community research team created to investigate and improve research quality regarding health-related needs, beliefs, and behaviors of recent Latino immigrants living in Cincinnati, Ohio. Our community research team, Latinos Unidos por la Salud (LU-Salud), is composed of Latino immigrant community members and academic researchers working in a health research partnership. The community team members are considered “co-researchers” since LU-Salud was designed within a community-based participatory research framework where we engaged in shared decision making at each phase of the research process from design, data collection, and interpretation of findings to dissemination. The co-researcher approach promoted shared decision-making and community empowerment throughout the research process with our community members providing expertise about the “what” (Latino immigrant health-related beliefs and behaviors, questionnaire content, interpretation of data) and the “why” (to obtain perspectives from Latino immigrants who typically don’t engage with academics) and our academic members bringing expertise about the “how” (research design and methods, grant funding).

Keywords

co-researchers, community-based participatory research, Latino immigrant health, community research team

Cover Page Footnote

This project was funded by a Community Health Grant from the Center for Clinical and Translational Science and Training, an organization supported by the National Center for Advancing Translational Sciences of the National Institutes of Health, under Award Number UL1TR000077. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

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In 2013, Latinos were the largest ethnic minority in the United States, representing 17.1% of the population (U.S. Census Bureau, 2013b). Latinos are increasing in numbers in parts of the country that have not been common immigrant destinations (Kandel & Parrado, 2005; Lichter & Johnson, 2006). The tremendous Latino growth combined with the challenges of living in a nontraditional migration area make Latinos, particularly those who are undocumented, a “difficult-to-reach” and understudied population in research (Newell & South, 2009; Parrado, McQuiston, & Flippen, 2005). Language barriers, documentation status, low levels of acculturation and education, and frequent geographic mobility all contribute to Latino immigrants being underrepresented in standard surveys (Newell & South, 2009; Parrado et al., 2005). A research project that partners directly with Latino community members is one of the only strategies that could be effective in eliciting the beliefs and experiences of Latino immigrant families especially in nontraditional migration cities. In this manuscript, we describe the research context and the development of *Latinos Unidos por la Salud* (LU-Salud), a community research team composed of Latino immigrant community members and academic investigators working in a health research partnership since the summer of 2013. LU-Salud was created to investigate and improve research quality regarding health-related needs, beliefs, and behaviors of recent Latino immigrants living in Cincinnati, Ohio, USA (findings/results of the conducted studies are described elsewhere - Jacquez et al., 2016; Vaughn, Jacquez, Marschner, & McLinden, 2016). After detailing the 6-stage process of assembling the academic-community health research team, we then highlight the reflections of the community co-researchers regarding involvement in the research process as part of a community research team. We conclude with lessons learned regarding the co-researcher approach with immigrants.

Community Research Teams/Co-Researchers

Co-researchers, or community members who have not been formally trained in research but conduct research alongside academic researchers, have been referred to by various titles including *lay researchers* (Carlisle &

Cropper, 2009; Newell & South, 2009), *peer researchers* (Guta, Flicker, & Roche, 2013; Logie, James, Tharao, & Loutfy, 2012), and *citizen scientists* (Bonney et al., 2009; Cohn, 2008; Dickinson, Zuckerberg, & Bonter, 2010). The differences among co-researcher, lay researcher, peer researcher, and citizen scientists are minimal and seem to primarily be an issue of semantics and disciplinary background. In all of these examples, the community members partnered with academic researchers to generate and maintain projects throughout the research process. In our approach, co-researchers were modeled after the evidence-based idea of *promotores*, non-medically trained staff who provide culturally appropriate interventions, (Auger & Verbiest, 2007) but applied to research. In the current manuscript, we refer to the community team members of LU-Salud as "co-researchers" since LU-Salud was designed within a community-based participatory research (CBPR) framework (Horowitz, Robinson, & Seifer, 2009) where academic researchers and Latino immigrant community members partnered at each phase of the research process including design, data collection, interpretation of findings and dissemination (Green et al. 1995). CBPR is the "systematic investigation with the participation of those affected by an issue for the purposes of education and action or affecting social change" [as cited in (Minkler, 2005), p. ii3]. Utilizing a CBPR orientation not only increases the potential to reach racial/ethnic minorities and "hidden communities" (Polanco et al., 2011), but also acts as a decolonizing process for research (Stanton, 2014) by providing the infrastructure to engage communities in their own transformation.

The benefits of a co-researcher model conducted within a CBPR framework are particularly salient for vulnerable and marginalized communities with a legacy of mistrust and underrepresentation in research (Corbie-Smith, Thomas, & George, 2002; Gamble, 1997). "Hard-to-reach" populations (Brackertz & Meredyth, 2009) are challenging for health care providers because additional efforts are needed to adequately address their health care needs. Although hard-to-reach populations are often those most likely to suffer from negative health outcomes, health systems often do not take on the extra effort to engage them. Scarcity of resources and a pressure to demonstrate success may lead providers to focus efforts on easier to reach populations that are more likely to show improvements more quickly (Cortis, 2012). Some populations, often those most affected by health disparities, are difficult to engage in research due

to challenges with social, cultural, and economic factors like trust, access, language, and transportation. Because of these challenges, hard-to-reach communities are underrepresented in the very research where their inclusion is most crucial (Steiner, 2016). Health disparities will persist if hard-to-reach populations are ignored, so innovative research techniques must be developed to engage hidden populations and determine appropriate ways to reach these communities.

LU-Salud was designed within a CBPR framework in order to foster open communication, capacity building regarding the research process, trust, equitable relationships between academics and Latino community members, and the possibility of transformative social change within the local Latino community (Israel et al., 2010; Minkler, 2005). Our academic-community partnership was based on the premise that co-learning must occur in order to promote “hybrid knowledge” between academia and community (Brookes, 2006). In particular, LU-Salud co-researchers brought expertise and experience about their lives, communities and health-related needs and concerns while LU-Salud academic members obtained grant funding to support the project and offered knowledge about research design and methods. A co-researcher model executed within a CBPR framework has myriad benefits, including higher participant engagement (and thus increased ownership of the research process), enhanced understanding of community needs, development of more relevant research questions, enriched research interpretation, wider dissemination and translation of results, and increased sustainability (Chang et al., 2013; Balazs & Morello-Frosch, 2013). The shared decision making aspect of CBPR with underserved populations in research also has the capability to improve research rigor (Buchanan, Miller, & Wallerstein, 2007; Diaz, Johnson, & Arcury, 2015).

Despite the benefits of the co-researcher model, the role of community members in research is often as consultants or advisors rather than collaborators who share decision making equally. The idea of working in partnership with community members as co-researchers is not new (Bindels, Baur, Cox, Heijing, & Abma, 2014; Burklow & Mills, 2009; Jurkowski et al., 2013; Stevenson, 2014; Walmsley & Mannan, 2009); however, manuscripts that explicitly describe research partnerships with immigrant community members as co-researchers are almost non-existent. In one example of a study involving Asian immigrant co-

researchers, Newell and South (2009) describe the co-researcher experiences of involvement but do not provide specific details or tangible steps of the co-researcher model.

Research Context and Setting/Community

The Cincinnati, Ohio metropolitan region is home to over 2 million people and is considered the 28th largest metropolitan area in the U.S. (U.S. Census Bureau, 2013a). Within that region the Latino population is estimated to be 50,000 – 60,000 people (Cincinnati USA Hispanic Chamber, 2015; Greater Cincinnati Latino Coalition, n.d.; U.S. Census Bureau, 2010). The metropolitan area has experienced Latino growth rates between 100-200% and several pockets have increased by over 200% from 2000 to 2010 (Jacquez, Vaughn, Pelley, & Topmiller, 2015). This rapidly expanding population has not been accompanied by a corresponding increase in resources to support Latino immigrants. The region can be considered a pre-emerging gateway (Dulin, Tapp, Smith, De Hernandez, & Furuseth, 2011), a community experiencing rapid immigration growth that does not have infrastructure to sufficiently support immigrants' healthcare needs (Waters & Jiménez, 2005). As the Latino population growth throughout the area occurs in geographically isolated pockets (Jacquez et al., 2015) and because local law enforcement has made anti-immigrant public pronouncements (de Casanova, 2010), the Latino immigrant community demonstrates marginalization from the community at large. Further, the healthcare system is not well prepared to address the unique needs of new arrivals to the U.S.

The combination of a booming Latino immigrant population, significant barriers to engagement with the local health care system, and perceived anti-immigrant sentiment created a knowledge gap in Cincinnati. Latino immigrants were not aware of the resources that were available to them, and the health care system, though somewhat poised to meet linguistic needs, was not well prepared to address cultural challenges to access. As a result, LU-Salud was formed to facilitate communication between the medical and Latino immigrant communities. The Latino participants provided the voice of the Latino immigrant community and the health care system could better understand the concerns that were most pertinent to Latino families.

Assembling an Academic-Community Health Research Team

Before starting the current project, two of the academic partners (LV, FJ) had worked with Latino-serving schools, social service agencies, and advocacy groups for approximately five years. Through this experience it became clear that the voice of the newly immigrated Latinos was not being fully represented in current research, intervention, and policy efforts and that without establishing a partnership with Latino immigrant community members, we as academics were unlikely to be successful in intervention strategies.

We obtained a community health grant through the Clinical and Translational Science Award center associated with our academic health center. The grant proposal prompted us to initially formalize an academic research team with bilingual and/or bicultural backgrounds. Grant funding allowed us to formally offer part-time paid positions to Latino immigrant co-researchers (described below). A “non-human subjects determination” was made by the IRB because study results were anonymous and not intended to be generalizable beyond Cincinnati.

Stage 1: Recruitment and Selection of Co-Researchers

Through already established connections with Latino-serving schools, social service agencies, and advocacy groups, our academic research team advertised a community health research team to be composed of Latino immigrants who had lived in Cincinnati for at least one year, could understand and speak Spanish, and who were the parent or grandparent of a child 18 years or younger. Interested Latino community members were asked to complete an application, which included demographic information, fluency in English and Spanish (English was not a requirement), and four essay questions about interest in the team, personal accomplishments and challenges, and their perspectives about Latino health issues. Twenty-three women applied to be on the team, all of whom were interviewed by one of the academic researchers to assess their interest and discuss their applications. None of the applicants had previous experience or training in research. Interviews were conducted in the applicant’s home or a nearby community location. Applications and interviews were discussed among the academic researchers. Nine of the 23 women were invited to be members and joined the team. The nine

women were all Latina immigrant mothers ranging in age from 29 to 49, with most women in their mid-30s. Two of the nine women spoke some English and the remaining spoke Spanish; one woman's first language was Mam. Their birth countries included Guatemala, Nicaragua and Mexico, and the women lived in the U.S. ranging from a few years up to 17 years. Only two of the women were partially employed outside their homes but all were active members of the Latino community, including participation in their children's schools, and Latino churches.

Stage 2: Research Training

The academic researchers started the project by conducting five consecutive research training sessions using interactive and participatory teaching methods and activities. Using Israel, Coombe and McGranaghan's (2010) CBPR phases as a guide, the training sessions were designed as an overview of community-based research, with emphasis on research quality and rigor, while maintaining collaboration and shared-decision making among the team. The specific content of the training sessions was prepared by the academic researcher members, based loosely on the Institute for Community Research's youth participatory action research curriculum and adapted for the LU-Salud team (Institute for Community Research, 2014). The conceptual framework for the training sessions was based on Knowles' "process model" within adult learning theory (andragogy) specifically emphasizing the co-researchers' life experience, the need for relevant information offered experientially, and the mutual negotiation of the sessions' objectives and activities (Knowles, 1984).

In order to capture the input and collaboration of the co-researchers throughout the research training sessions, each session was based on decisions made in the previous session. For example, once the team made the decision to do a survey, the academic researchers created training related to survey development and administration. The training sessions were conducted in Spanish by a native Spanish-speaking doctoral student member of LU-Salud with input and collaboration from other academic members. Overall, the research training sessions were intended to integrate, balance, and emphasize the cultural and contextual expertise of the nine women and the research expertise of the academic members. Table 1 describes the goals and content of each research training session.

Table 1. Goals and Content of Research Training Sessions

<p>Session 1: <i>Goal:</i> Focus research on issues that really matter for Latinos and explore need to include immigrant Latinos in health research</p>
<ul style="list-style-type: none"> • Interacted and got to know each other. • Brainstormed how we should work together. • Developed ground rules for training sessions. • Used large group participatory assessment method to identify issues about Latino health and to form the basis for future research decisions. • Presented information about the process of obtaining the grant to fund the project including the timeline and monies available to pay the co-researchers for their work and to incentivize community member participation.
<p>Session 2: <i>Goal:</i> Decide the specific topics and method for our research work together</p>
<ul style="list-style-type: none"> • Summarized opinions about Latino health. (Generated in Session 1) • Presented health concerns from previous work with Latinos in our area. • Discussed implementing surveys, interviews and focus groups to collect data. • Using demonstration role plays, the academic team members presented three different ways (surveys, interviews, focus groups) to collect data about health, and the co-researchers discussed the benefits and challenges of each method and what topics would be suited for each type of method. • Agreed on a verbally administered in-person (versus telephone) survey as the best way to reach Latino immigrant community members and facilitate participation.
<p>Session 3: <i>Goal:</i> Co-design survey questions based on topic areas identified in the previous session</p>
<ul style="list-style-type: none"> • Examined and created possible survey questions with four qualifiers: <ul style="list-style-type: none"> ○ Do the questions make sense? ○ Would your friends and neighbors understand how to answer them? ○ Do the questions represent the topic area well? ○ Is anything missing? • Co-researchers discussed which types of demographic questions may not be appropriate to ask (i.e., documentation status, income).

Session 4: *Goal:* Choose a name and logo for the group, finalize payment options for the women and approve the final version of the Latino Community Survey

- Decided on the name Latinos Unidos por la Salud through brainstorming and voting.
- Designed a logo, Latino families encompassed by two hands.
 - Decided to purchase turquoise colored t-shirts and black bags with the name and logo in white.
- Decided how co-researchers wished to be paid for their upcoming research work and data collection.
 - Agreed on \$10 per survey for first 25 surveys, with a \$100 bonus after 25 surveys collected. \$5 for each survey after 25 surveys collected.
- Set two goals:
 - Reachable goal: Verbal administration of 300 surveys (100 more than proposed in grant application).
 - Goal that is possible with extra effort: Verbal administration of 500 surveys.
- Decided that any remaining payment money should be used for a team celebration if their "extra effort" goal was met.
- Reviewed questions and instructions to make sure everything was translated appropriately into Spanish.
- Examined all questions for missing options such as natural remedies and prayer groups as options for health care/treating illnesses.
- Academic members presented specific skills for verbal survey administration such as: recruiting participants, building rapport, maintaining anonymity, not leading respondents, offering help when needed, checking for errors, observing reactions, completing field notes, thanking participants and giving incentives at survey completion.

Session 5: *Goal:* Practice survey administration and learn the importance of obtaining complete and accurate data

- Academic partners distributed copies of an incorrectly completed survey, and then discussed which items were answered correctly and incorrectly.
- Co-researchers created and practiced the initial script to use when approaching possible respondents.
- Identified places and methods to recruit participants (e.g., churches, apartment complexes, social groups, etc.).
- Each co-researcher made a specific sampling plan of who they would target in recruitment.
- Clarified inclusion/exclusion criteria of who should participate in the survey (i.e., over 18, immigrant from a Latin American country, and currently residing within the local country).

During the training sessions, each agenda consisted of items that the entire LU-Salud team needed to consider (as opposed to items about which academic members informed the community members). The academic members and co-researchers of LU-Salud made decisions together about our research questions, the best research method for reaching Latino immigrant community members, the content of the survey and data interpretation groups, how to spend the grant budget, and how community partners would be paid for their time. This emphasis on shared decision making between academics and community co-researchers helped to recalibrate the potential power differential throughout the project.

Logistics and Structural Support of Research Training Sessions

So that the partnership could incorporate the expertise of community members and maximize their ability to collaborate, we addressed logistical and structural issues that may have prohibited Latino immigrant involvement as co-researchers. Each training session lasted two hours on Sunday afternoons at a central location with time and location chosen by the co-researchers. Academic researchers budgeted grant monies to provide “structural support” such as childcare and meals for co-researchers and their children at each training session. Co-researchers were compensated for their time to attend training sessions and were reimbursed for transportation/travel. Recognizing the essential role of co-researchers throughout the entire research process, academic researchers and co-researchers discussed options for disbursing compensation for data collection efforts and voted on a budgeting plan.

Procedural Issues and Evaluation of Research Training Sessions

At the end of each training session, all academic and co-researcher members completed Likert-scale session evaluations regarding the degree to which each goal of the session was met and an overall rating of the session. Also at the end of each training session, academic team members completed a Likert-scale observer form regarding degree of co-researcher engagement in the session, atmosphere of collaboration versus hierarchy, and open-ended questions about highlights and challenges/obstacles of the session.

Stage 3: Working Meetings, Data Collection, Analysis, and Interpretation

Once data collection began, we had nine working meetings to discuss problems with survey administration and explore recruitment patterns in order to expand the diversity of the sample. In three months, the co-researchers administered 516 surveys, a number that far surpassed both the funding agency and the academic team's expectations of 200 surveys. Academic researchers entered survey responses into SPSS and ran descriptive analyses to share with the women. The co-researchers were asked to initially administer five surveys and then meet to discuss their experiences and ask questions. During this meeting, the academic researchers reviewed the surveys and collaboratively established strategies to avoid missing data in the future. As a result, over 98% of the 516 surveys had completed data (less than 2% missing data). We continued to meet in order to summarize and interpret findings from the survey.

Like the research training sessions, we maintained the same logistical and structural support at each working meeting. After data collection was completed, we had a team celebration at a local school to celebrate the group's major accomplishment of reaching more than 500 surveys (the team celebration idea was originated by the co-researchers who thought it was critical to reward our success along the way). We did not conduct formal evaluations of the working meetings, but rather had a check-in time at the beginning of each meeting. At the completion of each survey, the co-researchers asked each respondent to complete a short evaluation form rating the clarity of the questionnaire, the professionalism of the researcher, and whether the researcher was able to answer their questions. For each survey administered, the community co-researcher completed a brief field note describing their reactions post-survey, their reflection about their skill in administering the survey, and any noteworthy observations about the respondent while they were administering the survey.

Stage 4: Data Interpretation Groups with Latino Immigrant Community

To validate the results of the survey and to further explore the meaning of the results beyond the surveys, we held four focus groups with members of the larger Latino immigrant community (N = 28), some of whom had completed the survey. The doctoral student in our group and two of the co-researchers facilitated each of the four focus groups in Spanish at various community locations. In each of the focus groups, the three facilitators asked questions of participants to elicit perspectives about the overall findings of the survey and to ask for interpretations of any surprising or unexpected findings. The focus groups supported the major themes from the surveys, such as the importance of health care resources for Spanish-speakers, concerns about the cost and availability of health insurance, and how immigration status affected the health and well-being of Latino immigrants. The focus groups also reinforced the challenges involved in working with this population, as many participants discussed their sense of isolation from the rest of society and our larger community.

Stage 5: Dissemination of Results

To date, results from the surveys and focus groups have been disseminated in several formats to both community and academic audiences. The LU-Salud team created a PowerPoint presentation detailing the results in both English and Spanish with co-researcher audio or video on each slide. The co-researchers made a 7-minute video that described the research process and their participation and experience of being co-researchers (<https://www.youtube.com/watch?v=kZsYa5cXahk&feature=youtu.be>). The results PowerPoint and process video have been shared on numerous occasions with academic audiences as well as community groups, including Latino service providers, immigrant advocacy organizations, and healthcare professionals. A one-page summary of results targeted to Latino immigrant community members has been shared in Latino community locations (churches, markets, etc.). Seven of the co-researchers are co-authors on the current manuscript and contributed to the development, outline and conceptualization of the paper.

Stage 6: Action Planning and Next Steps

Using the survey and focus group results as our guides, all members of LU-Salud discussed the necessity of developing interventions to improve Latino health in our area from Latino community members and Latino-serving professionals. With the financial support of a small institutional grant, LU-Salud members (both co-researchers and academic members) solicited community input about strategies to address the top health concerns identified in the surveys and focus groups (obesity, stress, and healthcare navigation; see Vaughn et al., 2016).

Reflections of the Co-Researchers Regarding the Research Process and LU-Salud

In order to capture the perspectives of the co-researchers regarding their involvement with LU-Salud, one of the academic team members conducted in-depth interviews with each of the remaining co-researchers (N=7) before we began the dissemination phase. Two of the nine original co-researchers were not able to continue participating in the research project because of conflicting work or personal responsibilities (one co-researcher completed research training but did not administer surveys, and one left the project after administering surveys). All of the interviews were audio-recorded in Spanish and transcribed into English. All interviews were coded inductively using a thematic analysis in which codes were determined from interview transcripts and sorted into three major aspects of being part of LU-Salud: 1) beginning LU-Salud; 2) benefits of being part of LU-Salud; and 3) overall reflections about research and LU-Salud.

1) Beginning LU-Salud

All but one of the co-researchers commented on the lengthy initial recruitment and selection process. As a group, the co-researchers indicated their pride in being selected for the team and their dedication to the project. Haydee, a co-researcher, noted that "the best part was that they chose Hispanic women, people from our community." Most of the co-researchers mentioned their surprise of the co-researcher model and how it stood in contrast to what they expected LU-Salud to be in the beginning. For instance, Eufemia said, "I thought that everything was already set with the group and that everything was organized and that we

would just follow the instructions, but no, we were called to form the group, choose the questions ourselves and work directly with the Latino people.”

2) Benefits of being part of LU-Salud

When asked about the benefits of participating and being a member of LU-Salud, all the co-researchers said that they felt empowered because they were charged with an important task. Maritza, a co-researcher, stated: “...I never thought that I would go out and represent the Latino community, but I think it was one of the best ways to be able to obtain the information. We were able to determine what the Latino community really needs.” Inelda, another co-researcher, indicated: “I liked that they [academic researchers] took our opinions into account. I was surprised because I thought that they would say this is what we will do but they wanted to know what we thought.” Jenniffer, a third co-researcher, noted that she felt excited by being an integral part of LU-Salud and learning how to conduct research in her community. She didn’t expect that, “we were going to create the questions and that we were going to do all the work! I thought it was going to be that we would go somewhere and we would talk and they would ask our opinions, but I didn’t think that we would be protagonists in this work. I think it was something good.”

All but one co-researcher mentioned that they learned significant interviewing/ communication techniques about how to approach people for participation, administer surveys, conduct focus groups, and review the results. Five of the co-researchers described the benefits of professional learning and felt that this experience would provide them with new professional opportunities in the future. Four of the seven noted the importance of being paid for their research work in data collection and conducting the focus groups.

3) Overall reflections about research and LU-Salud

In terms of participation in LU-Salud, all the co-researchers mentioned two consistent issues—the data analysis process and resistance to participating in research from members of the larger Latino community. Jenniffer described the importance of the data analysis:

The best part was that we had data now, consistent data. This could help us with the focus groups so that we could find people that we had surveyed. Then we had an idea of the themes, what more than 500 people thought was most important to discuss. This was the most important because now we had help. It wasn't like we were just jumping into the void.

Maria C., a co-researcher, said that compiling the data helped her understand challenges within the community: "...what was impressive to me was the evaluation once it was done showed the percentage of people in the Latino community that had problems. The results were surprising." Haydee provided more specific details about the results: "I was surprised that the majority [of respondents] did not have insurance. I thought that the children's rate would have been higher. I was surprised that there are so many children who don't go [to the doctor] because they don't have medical insurance." Many agreed with this perspective-- "the little I could learn and share with people in the street was a beautiful experience because I could know about the fears of people in the Latino community." The co-researchers were surprised about resistance to participation especially with immigrant Latinas administering the surveys. Six of the seven indicated that confidentiality was a barrier to finding respondents-- "many people didn't want to participate in the survey because maybe they were afraid or they said that they had to ask their husband." The majority of the co-researchers noted that the data collection process was arduous and time-intensive:

It was complicated and difficult because you had to go door to door looking for people, and people wouldn't want to answer. They would say I go to the doctor and I don't need to participate. Some other people would take very long to complete the survey. You would start talking to them and then they would get distracted and you spend all day.

Reflecting on the overall process of being part of LU-Salud, Maria M., a co-researcher, summed up the experience of many members of the team by saying, "the best part [of LU-Salud] was that we met more people in the community, we got to know each other as a team, we made some friendships and had a good time. We also gathered a lot of information!"

Lessons Learned about the Process of Developing an Immigrant Community Research Team Using a Co-Researcher Model and CBPR Framework

The following section lists eight ideas that emerged from the experience of creating the community research team that will shape LU-Salud's efforts in the future:

1. Shared decision-making and shared leadership between academics and immigrant community members are key factors within a co-researcher model using a CBPR approach. Not only did our research training sessions use an iterative process of shared decision making within each session to inform the next session, but academic members and community co-researchers also collectively made decisions about the research design and process of working together and had shared ownership for leading the group and the intended outcomes.
2. An unwavering focus on relationship/partnership within LU-Salud was critical from beginning to end and will affect the maintenance of our ongoing collaboration. The academic team and the co-researchers dedicated extensive time and effort to create a positive working environment and to incorporate each member of the research team into the decision making process. The LU-Salud members provided entrée into the local Latino community, and contextualized the research conclusions. The academic members and co-researchers also emphasized the power dynamics within the group and addressed the social and emotional needs of LU-Salud.
3. Research with undocumented immigrants leads to additional challenges in CBPR such as fear, distrust, and barriers to offering payment/incentives. However, because it is so important that undocumented immigrants, often a "hidden" and "hard-to-reach" population, are represented in research efforts, it is worth the dedication and energy to push through barriers and find effective models that can increase engagement and trust (i.e., community co-researchers) and explore workable solutions that bridge institutional policies and procedures and yet still reach undocumented immigrants.

4. Transparency and collaboration about the research budget with the co-researchers helped to establish trust and reduce power differentials between academics and community members. Co-researchers helped to set up the pay structure for data collection. As a motivation toward collecting 500 surveys, co-researchers suggested reserving funds from the budget to have a celebration of accomplishment. By sharing decision making about money, community partners were valued as equal members of the research team.

5. Providing structural and logistical support (childcare, meals, convenient meeting location and time, transportation, incentives, etc.) during research training sessions and working group meetings is key for maximizing participation and attendance of co-researchers.

6. Partnering with actual community members is different and potentially more challenging than partnering with leaders of community organizations and agencies. Because our community co-researchers (versus academic researchers) reached out to their own communities to collect data, we were able to overcome the fear of discrimination and deportation that was reported by many participants in the current study. In addition, working directly with community members created the possibility of initiating transformative social change from within the community at a grass-roots level. Community co-researchers said they felt like empowered actors who could contribute to positive change within their community. We presented the study results to several Latino community advocacy organizations, Latino health service providers, and broader audiences of hospital and community providers. These stakeholders used the results to inform interventions and policies.

7. Institutional/university support is essential for a successful community co-researcher model. Academics are paid for their research work and are often able to "count" community service as part of their promotion and tenure process. More often than not, community members are expected to volunteer their time and demonstrate commitment to community change without compensation. In LU-Salud, we found that compensating for co-researcher time and incentivizing data collection efforts not only contributed to the co-researchers' sense of project ownership and commitment, but also ensured that the academic research team maintained their motivation as well. Without institutional/university

support and a concrete process to facilitate payment and incentives, we would not have been able to develop such strong relationships between the co-researchers and the academic research team.

8. Research training sessions conducted with co-researchers must emphasize active learning and hands-on activities. In LU-Salud, we used role play of data collection and practice sessions to stress the importance of missing data and honesty in responses. We believe that the experiential learning protocol in LU-Salud training was responsible for the small number of missing data points (12 out of 516 surveys—2%; see Jacquez et al., 2016).

Conclusions

Although academic medicine has increasingly recognized the potential for community-engaged research to more quickly translate science into community settings (Lloyd Michener et al., 2012), perhaps less recognized is the significant degree to which a co-researcher model can improve the quality of scientific research. Partnering with co-researchers in LU-Salud allowed the team to access reliable, quality data from difficult-to-reach Latino immigrants living in a nontraditional migration city. By training members of this community as co-researchers and using rigorous research methods, we not only spurred community mobilization and empowerment toward positive change but also vastly improved research quality. We obtained information from a hard-to-reach population (Brackertz & Meredyth, 2009; Cortis, 2012; Steiner, 2016), and will be able to use more representative research findings to inform future community prevention and intervention efforts. The co-researchers remain “champions” for Latino health in their community, and they are trusted resources and confidants for peers and neighbors. The co-researcher model promoted shared decision-making and community empowerment throughout the research process, with the community co-researchers providing expertise about the “what” (Latino immigrant health-related beliefs and behaviors, questionnaire content, interpretation of data) and the “why” (to obtain perspectives from Latino immigrants who typically don’t engage with academics) and academic researchers bringing expertise about the “how” (research design and methods, grant funding).

Accurate information from all stakeholders is critical to understanding the biologic, behavioral, environmental, and social factors impacting community health status. Without such data, it is difficult to improve population health and to reduce health disparities. Co-researcher partnerships with actual community members should be part of a comprehensive community health strategy. By directly involving members of subpopulations in the measurement of community needs and in the implementation of improvements, academic researchers will find greater success with interventions that are customized for unique groups. Within community-engaged research efforts, the co-researcher model is extremely promising in terms of better-informed interventions for both individuals and communities and should be strongly considered for research studies focusing on immigrants and other hard-to-reach and marginalized groups. Future studies related to the co-researcher model should include how both community and academic members assess the impact of their efforts; how co-researchers integrate with or form learning health systems; and the use and scope of different methods, including quality improvement, to affect change. Additionally, future studies could document the positive effects on the co-researchers themselves as well as the broader impact on the community beyond the specific focus of the study, including sustainable improvements in health care delivery and outcomes, spread to other communities, employment and new job creation, advocacy efforts and subsequent changes in health care policies, and success in obtaining funding for future research. Applying the LU-Salud co-researcher model in other contexts would help determine if using this approach could lead to more effective community-academic research partnerships.

References

- Auger, S., & Verbiest, S. (2007). Lay health educators' roles in improving patient education. *North Carolina Medical Journal*, *68*(5), 333.
- Balazs, C. L., & Morello-Frosch, R. (2013). The three Rs: How community-based participatory research strengthens the rigor, relevance, and reach of science. *Environmental Justice*, *6*(1), 9-16.
- Bindels, J., Baur, V., Cox, K., Heijing, S., & Abma, T. (2014). Older people as co-researchers: A collaborative journey. *Ageing and Society*, *34*(06), 951-973.

- Bonney, R., Cooper, C. B., Dickinson, J., Kelling, S., Phillips, T., Rosenberg, K. V., et al. (2009). Citizen science: A developing tool for expanding science knowledge and scientific literacy. *Bioscience*, *59*(11), 977-984.
- Brackertz, N., & Meredyth, D. (2009). Community consultation in victorian local government: A case of mixing metaphors? *Australian Journal of Public Administration*, *68*(2), 152-166.
- Brookes, B. (2006). Introduction to history, health, and hybridity. *Health and History*, *8*(1), 1-3.
- Buchanan, D. R., Miller, F. G., & Wallerstein, N. (2007). Ethical issues in community-based participatory research: Balancing rigorous research with community participation in community intervention studies. *Progress in Community Health Partnerships: Research, Education, and Action*, *1*(2), 153-160.
- Burklow, K., & Mills, L. (2009). Giving voice to underserved and culturally diverse groups using community-based participatory research. *Open Medical Education Journal*, *2*, 75-79.
- Carlisle, S., & Cropper, S. (2009). Investing in lay researchers for community-based health action research: Implications for research, policy and practice. *Critical Public Health*, *19*(1), 59-70.
- Chang, C., Minkler, M., Salvatore, A. L., Lee, P. T., Gaydos, M., & Liu, S. S. (2013). Studying and addressing urban immigrant restaurant worker health and safety in San Francisco's Chinatown district: A CBPR case study. *Journal Of Urban Health: Bulletin Of The New York Academy Of Medicine*, *90*(6), 1026-1040. doi: 10.1007/s11524-013-9804-0
- Cincinnati USA Hispanic Chamber (2015). Did you know 2015: Hispanic facts, data and trivia.
- Cohn, J. P. (2008). Citizen science: Can volunteers do real research? *Bioscience*, *58*(3), 192-197.
- Corbie-Smith, G., Thomas, S. B., & George, D. M. M. S. (2002). Distrust, race, and research. *Archives of Internal Medicine*, *162*(21), 2458-2463.
- Cortis, N. (2012). Overlooked and under-served? Promoting service use and engagement among 'hard-to-reach' populations. *International Journal of Social Welfare*, *21*(4), 351-360.
- de Casanova, E. M. (2010). New allies for immigration reform: A Cincinnati story. *Latino Studies*, *8*(1), 121-125.

- Diaz, A. E. K., Johnson, C. R. S., & Arcury, T. A. (2015). Perceptions that influence the maintenance of scientific integrity in community-based participatory research. *Health Education & Behavior, 42*(3), 393-401.
- Dickinson, J. L., Zuckerberg, B., & Bonter, D. N. (2010). Citizen science as an ecological research tool: Challenges and benefits. *Annual Review of Ecology, Evolution, and Systematics, 41*, 149-172.
- Dulin, M. F., Tapp, H., Smith, H. A., De Hernandez, B. U., & Furuseth, O. J. (2011). A community based participatory approach to improving health in a Hispanic population. *Implementation Science, 6*(1), 38.
- Gamble, V. N. (1997). Under the shadow of Tuskegee: African Americans and health care. *American Journal of Public Health, 87*(11), 1773-1778.
- Greater Cincinnati Latino Coalition. (n.d.). Latinos in greater Cincinnati, from www.cincinnati-latino.org
- Green, L. W., George, M. A., Daniel, M., Frankish, C. J., Herbert, C., Bowie, W. R., et al. (1995). Study of participatory research in health promotion. *Royal Society of Canada*.
- Guta, A., Flicker, S., & Roche, B. (2013). Governing through community allegiance: A qualitative examination of peer research in community-based participatory research. *Critical Public Health, 23*(4), 432-451. doi: 10.1080/09581596.2012.761675
- Horowitz, C. R., Robinson, M., & Seifer, S. (2009). Community-based participatory research from the margin to the mainstream are researchers prepared? *Circulation, 119*(19), 2633-2642.
- Institute for Community Research. (2014). The Institute for Community Research's youth participatory action research curriculum: Adapted for Oregon, from <http://public.health.oregon.gov/HealthyPeopleFamilies/Youth/Documents/CurriculumYPAR2014.pdf>
- Israel, B. A., Coombe, C. M., Cheezum, R. R., Schulz, A. J., McGranaghan, R. J., Lichtenstein, R., et al. (2010). Community-based participatory research: A capacity-building approach for policy advocacy aimed at eliminating health disparities. *American Journal of Public Health, 100*(11), 2094-2102.
- Jacquez, F., Vaughn, L. M., Pelley, T., & Topmiller, M. (2015). Healthcare experiences of Latinos in a nontraditional destination area. *Journal of Community Practice, 23*(1), 76-101.

- Jacquez, F., Vaughn, L., Zhen-Duan, J., & Graham, C. (2016). Healthcare utilization and barriers to care among Latino immigrants in a new migration area. *Journal of Healthcare for the Poor & Underserved, 27*(4).
- Jurkowski, J. M., Mills, L. L. G., Lawson, H. A., Bovenzi, M. C., Quartimon, R., & Davison, K. K. (2013). Engaging low-income parents in childhood obesity prevention from start to finish: A case study. *Journal of Community Health, 38*(1), 1-11.
- Kandel, W., & Parrado, E. A. (2005). Restructuring of the us meat processing industry and new Hispanic migrant destinations. *Population And Development Review, 31*(3), 447-471.
- Knowles, M. S. (1984). *Andragogy in action*: Jossey-Bass San Francisco.
- Lichter, D. T., & Johnson, K. M. (2006). Emerging rural settlement patterns and the geographic redistribution of America's new immigrants. *Rural Sociology, 71*(1), 109-131.
- Lloyd Michener, M., Cook, J., Ahmed, S. M., Yonas, M. A., Coyne-Beasley, T., & Aguilar-Gaxiola, S. (2012). Aligning the goals of community-engaged research: Why and how academic health centers can successfully engage with communities to improve health. *Academic Medicine, 87*(3), 285.
- Logie, C., James, L., Tharao, W., & Loutfy, M. R. (2012). Opportunities, ethical challenges, and lessons learned from working with peer research assistants in a multi-method HIV community-based research study in Ontario, Canada. *Journal of Empirical Research on Human Research Ethics, 7*(4), 10-19.
- Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities. *Journal of Urban Health, 82*, ii3-ii12.
- Newell, C. J., & South, J. (2009). Participating in community research: Exploring the experiences of lay researchers in Bradford. *Community, Work & Family, 12*(1), 75-89.
- Parrado, E. A., McQuiston, C., & Flippen, C. A. (2005). Participatory survey research integrating community collaboration and quantitative methods for the study of gender and HIV risks among Hispanic migrants. *Sociological Methods & Research, 34*(2), 204-239.
- Polanco, F. R., Dominguez, D. C., Grady, C., Stoll, P., Ramos, C., Mican, J. M., et al. (2011). Conducting HIV research in racial and ethnic minority communities: Building a successful interdisciplinary research team. *Journal of the Association of Nurses in AIDS Care, 22*(5), 388-396.

- Stanton, C. R. (2014). Crossing methodological borders decolonizing community-based participatory research. *Qualitative Inquiry, 20*(5), 573-583.
- Steiner, A. (2016). Assessing the effectiveness of a capacity building intervention in empowering hard-to-reach communities. *Journal of Community Practice, 24*(3), 235-263.
- Stevenson, M. (2014). Participatory data analysis alongside co-researchers who have Down's Syndrome. *Journal of Applied Research in Intellectual Disabilities, 27*(1), 23-33.
- U.S. Census Bureau. (2010). Interactive population map Retrieved February, 2013, from www.census.gov
- U.S. Census Bureau. (2013a). Metropolitan and micropolitan statistical areas Retrieved February, 2013, from www.census.gov
- U.S. Census Bureau. (2013b). State and county quickfacts Retrieved March 9, 2015, from <http://quickfacts.census.gov/gfd/states/00000.html>
- Vaughn, L. M., Jacquez, F., Marschner, D., & McLinden, D. (2016). Using concept mapping to visualize Latino immigrant's strategies for health interventions. *International Journal of Public Health (61)*, 837-845.
- Walmsley, J., & Mannan, H. (2009). Parents as co-researchers: A participatory action research initiative involving parents of people with intellectual disabilities in Ireland. *British Journal of Learning Disabilities, 37*(4), 271-276.
- Waters, M. C., & Jiménez, T. R. (2005). Assessing immigrant assimilation: New empirical and theoretical challenges. *Annual Review of Sociology, 105*-125.