Grassroots to Grasstops: A Stepwise Approach to Identify Community Health Priorities

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A community-based participatory research (CBPR) partnership between an academic research center (the Center for Healthy Communities at the University of California, Riverside) and three Latinx communities in Riverside, California, was established to build the capacity of community members, faculty, students, and community-based organizations to partner in health research and identify community health concerns. A project Steering Committee, with community and academic members, led the project. Community capacity for engaged research was developed through a series of trainings, including training community residents to facilitate deliberative sessions. Community members led data collection, starting with in-home meetings to discuss community health concerns, followed by town hall meetings in each community. Deliberative sessions, using the Deliberative Democracy Forum Method, were held to identify community health priorities. This process involved framing sessions and four community forums, followed by a community-wide mental health gathering. Having the active involvement of a strong community lead was critical to the project's success. Barriers to project sustainability are discussed.

Introduction

As Zimmerman and Concannon remind us in the introduction of this book, community-based participatory research is increasingly used to engage underserved and vulnerable communities in health disparities research. The use of engaged methods

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with immigrant and minority populations, underrepresented populations in research, is an ideal way to create collaborative partnerships, build trust, and obtain meaningful participation in research. This chapter highlights the use of CBPR to engage three Latinx communities in capacity building to partake in future research.

Latinx are a fast growing segment of the U.S. population. Unfortunately, a number of health disparities exist between Latinx and other U.S. populations. Latinx adults report significantly higher rates of and deaths from diabetes, cancer (specifically cervical, liver, and stomach cancers), HIV infection, homicide, and work-related injuries compared to whites (Vega, Rodriguez, & Gruskin, 2009). Latinx children are the most obese child population (21.2% Latinx vs. 14% white non-Latinx) (Ogden, Carroll, Kit, & Flegal, 2014), putting them at elevated risk for diabetes, cardiovascular disease, and other serious chronic illnesses (Juonala et al., 2011; Pulgaron & Delamater, 2014). This child population is also at high risk for asthma, school dropout, and poor mental health (Champion & Collins, 2013; Flores et al., 2002; Le Cook, Brown, Loder, & Wissow, 2014).

Additionally, the Latinx population has poor access to health care services. Latinx are twice as likely as African Americans and three times as likely as whites to lack a regular health care provider (Betancourt, Green, Carrillo, & Ananeh-Firempong, 2003; Campo-Flores, 2014). In addition, numerous barriers constrain Latinx help-seeking, such as the lack of culturally competent providers, barriers related to language, reliance on folk remedies, and mistrust of the formal health care system (Pardasani & Bandyopadhyay, 2014; Rodriguez et al., 2014; Vega et al., 2009).

Despite significant health disparities in this population, Latinx have historically been underrepresented in health research (Deren, Shedlin, Decena, & Mino, 2005). In part, this reflects social injustices linked to racism and researcher bias (George, Duran, & Norris, 2014; Olson, Cottoms, & Sullivan, 2015). It also reflects ineffective engagement strategies that stem from a lack of cultural awareness and sensitivity, as well as inattention to historically based structural factors that undermine minority groups' trust in research and researchers (Corbie-Smith, Thomas, & St George, 2002; Williams, Mohammed, Leavell, & Collins, 2010). There is nevertheless a need to engage this patient population and build their capacity to collaborate in research. Community members' leadership skills and capacity can potentially contribute to community resilience, especially in the face of social inequalities such as poverty, limited employment options, and disparities based on race (Coffman, Norton, & Beene, 2012; Gebbie, Rosenstock, & Hernandez, 2003; Institute of Medicine [IOM], 2015).

Engaging Latinx Communities

Although engagement strategies should acknowledge the importance of family (*familismo*), respect for others (*respeto*), personal relationships (*personalismo*), and agreeableness (*simpatía*) in Latinx culture, investigators often overlook these core cultural values. For instance, a group in San Diego (O'Neill, Williams, & Reznik, 2008) initially failed to engage the local Latinx community in violence prevention. Their initial engagement approaches, which involved focus groups, health and street fairs, and involvement of faith communities and local organizations, were common public health strategies to engage community. However, these strategies are impersonal—they do not allow for relationship building and development of personal connections with community members (Bell & Standish, 2005; Simpson, Wood, & Daws, 2003).

Investigators also recognize the importance of hiring from the community—a concept imbued with multiple meanings. Community may literally refer to a member of the local area or figuratively refer to someone who understands the experiences of the people in the local context such as a person who is bilingual, immigrant, or Mexican (Rodriguez et al., 2014).

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In this chapter, we present our approach to engaging three predominantly Latinx communities through Latino Health Riverside (LHR) *(Salud de Los Latinos en Riverside)*, a Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI). This award was designed to (1) create a foundation for community-partnered and patient-oriented research with the Riverside Latinx community, researchers, and students from local colleges and universities; (2) build community, faculty, and student capacity to engage in partnered research; and (3) identify key health concerns in three Latinx neighborhoods in Riverside.

Latino Health Riverside

This project built a partnership between the Center for Healthy Communities (CHC) located in the University of California, Riverside (UCR) School of Medicine and three predominantly Latinx neighborhoods in Riverside, California. The UCR School of Medicine was established in 2013 to address the persistent physician shortage in medically underserved areas of inland Southern California (Olds & Barton, 2015). The CHC was established specifically to conduct community-engaged research. Faculty were recruited with expertise in CBPR with the intent to engage not only community members but also other UCR faculty and students. The majority of the faculty were new to the Riverside area and some new to California.

The goal of LHR was to build the capacity of community members, faculty, students at local colleges and universities, and community-based organizations to partner in health research. Unlike some other locales, there was no existing organization with a mission related to Latinx health. Furthermore, the faculty involved in this project were new to the Riverside area. We therefore started from scratch by creating a project Steering Committee (SC), chaired by an academic partner and the community investigator and composed of community members, students, local health leaders, and faculty. This committee oversaw, guided, and provided input on project activities such as research training and engagement events, data collection and analysis, and dissemination efforts. Not only did we engage stakeholders in the design and implementation of the project, but we also engaged stakeholders in research activities. We conducted in-home meetings with grassroots Latinx community members. Grasstops community members (e.g., community leaders) are often involved in planning health interventions, but grassroots members are less likely, if ever, engaged in health intervention planning (O'Neill et al., 2008). To engage both grassroots and grasstops in research, we used deliberative methods to bring together diverse stakeholders and perspectives in the same room in community forums.

Over the course of the project, we gathered information via surveys and post-forum interviews to evaluate how well project activities met our goals to create a foundation for community-partnered research and build stakeholder capacity to engage in future research. We did this in two ways. First, we assessed grassroots stakeholders' interest in community-partnered research by asking participants in the in-home meetings if they would be willing to (1) attend other similar meetings to discuss health issues, (2) help design health programs that could be useful to their community, and (3) take action to improve the health of their community. The majority indicated interest in further participation in meetings, to design health programs and to take action. We also conducted one-on-one qualitative interviews with approximately 15 forum participants to assess their willingness to participate in regular meetings with other community members, leaders, and researchers to help work on health programs that could be useful to their communities. Most participants indicated they would work

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with others on such activities, especially if the work focused on addressing salient community health concerns (e.g., mental health) and disparities in access to health care or basic needs (e.g., food).

City of Riverside

We engaged stakeholders in three predominantly Latinx communities in the City of Riverside, located in inland southern California. Riverside, population 316,619, is the largest city in Riverside County. No other city of its size in California has a greater percentage of persons living below the poverty line. Riverside is designated, along with neighboring cities of San Bernardino and Ontario, as the "poorest large metropolitan area in the U.S." Almost one in five of the city's residents live below the poverty line (U.S. Census Bureau, 2014). Latinx are overrepresented among the poor and underrepresented in positions of power (e.g., city council, county board of supervisors).

The City of Riverside is home to three neighborhoods with a majority (75% or higher) Latinx population: Arlanza, Casa Blanca, and Eastside. Among these neighborhoods, Arlanza is the largest regarding geography and population. It is predominantly a residential area. Casa Blanca, the smallest of the three neighborhoods, is the oldest. It is predominantly a residential community. Compared to the other two neighborhoods, it has the highest number of owner occupied housing units. The Eastside neighborhood, adjacent to the UCR campus, is located in an area with far more commercial activity—restaurants and retail and grocery stores. Its population is somewhat more transient, and it is believed to have the largest number of undocumented persons from Mexico compared to the other two communities. Slightly more than one third of its housing units are owner occupied.

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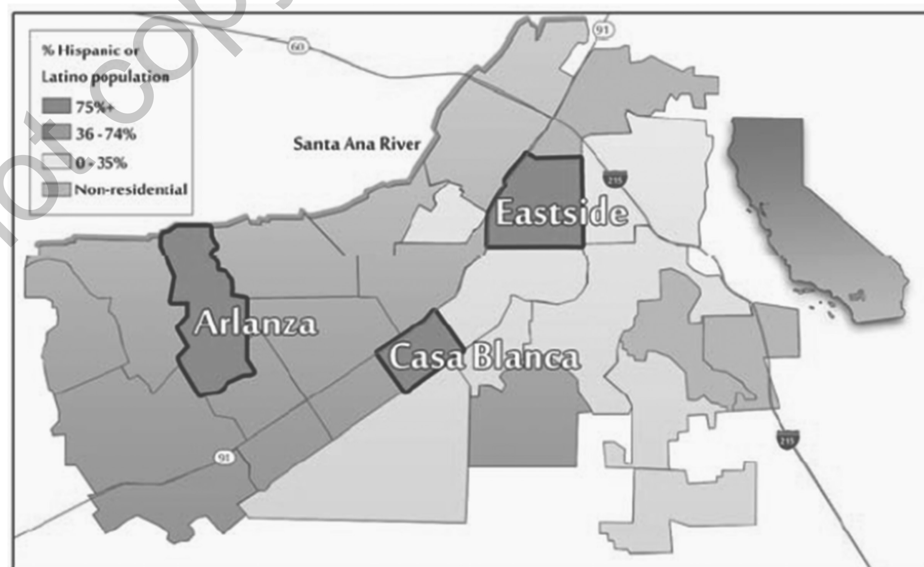
FIGURE 1.1 ● Neighborhoods in City of Riverside



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Latino Health Riverside Steering Committee

As noted earlier, a Steering Committee (SC) representing various stakeholders provided input into the conduct and implementation of the project on a monthly basis. This committee initially included representation from each of the three neighborhoods, UCR undergraduate and medical students, a community college student, and employees of the Riverside County public health division of asthma prevention and education and of Inland Empire Health Plan (Medi-Cal insurer). The Community Lead and academic partners recruited SC members through their social and professional networks. For instance, the Community Lead invited known leaders and community-based organization (CBO) representatives in each of the three communities, whereas the academic partners reached out to contacts in Riverside County's Department of Public Health, the UCR School of Medicine, and the local community college. As the project progressed, we added additional members to the committee, including employees of Riverside County behavioral health in the divisions of prevention and early intervention and cultural competency. Participation from each of the three neighborhoods was critical to our engagement of grassroots Latinx community members. For instance, these representatives were from and of the community—they had either grown up in the neighborhood, had a familial presence in the neighborhood, or were a current neighborhood resident. Because of their connection to their respective neighborhood, they were aware of community meeting places and resources. They knew how to navigate their neighborhoods regarding social norms and the language—all spoke Spanish. They also had strong connections to Latinx and were aware of how to engage grassroots Latinx community members.

Committee members collectively reviewed and provided input on a Memorandum of Understanding (MOU), which they then signed. The MOU described the project scope, aims, and deliverables and provided a timeline. It emphasized the project's focus on capacity building and planning rather than the creation or implementation of a public health intervention. The MOU also described committee member and leadership responsibilities and the resource-sharing plan (e.g., payment for committee meeting participation). Furthermore, committee members agreed the MOU should contain a section where each member could designate an alternate to ensure information flow. Some members adhered to this expectation more so than others did. For example, medical students and health care professionals took this very seriously whereas two of the community representatives did not engage the alternate in their absence and one engaged the alternate who chose to attend as an unpaid participant and became one of the most engaged committee members.

This committee met monthly for the duration of the project, and the location rotated between the three neighborhoods. In the first year, we also met on campus. However, because of parking issues and the challenge of finding campus buildings, we abandoned on-campus meetings and opted for community meetings only. Committee meetings were held in the evenings, and dinner was served, which provided an opportunity for rapport building across committee members. Over the course of the project, this committee vetted project material such as interview guides, consent forms, and event invitations; reviewed and selected facilitators for community forums; and participated in project activities from capacity-building trainings to town halls to community forums. Each attendee received $75 per meeting.

While this committee was intended to collectively guide the project, we found students and representatives from public services deferred to the community representatives. Halfway through our project, we held an activity in which each stakeholder group (students, community representatives, and public service providers)

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brainstormed ways the stakeholder groups (other than themselves) contributed to the overall project goals. This activity enabled us to openly discuss the value of students' savviness with technology and communication and public service providers' professional connections to the success of the project. This activity encouraged us to identify the unique perspectives all stakeholders brought to the table.

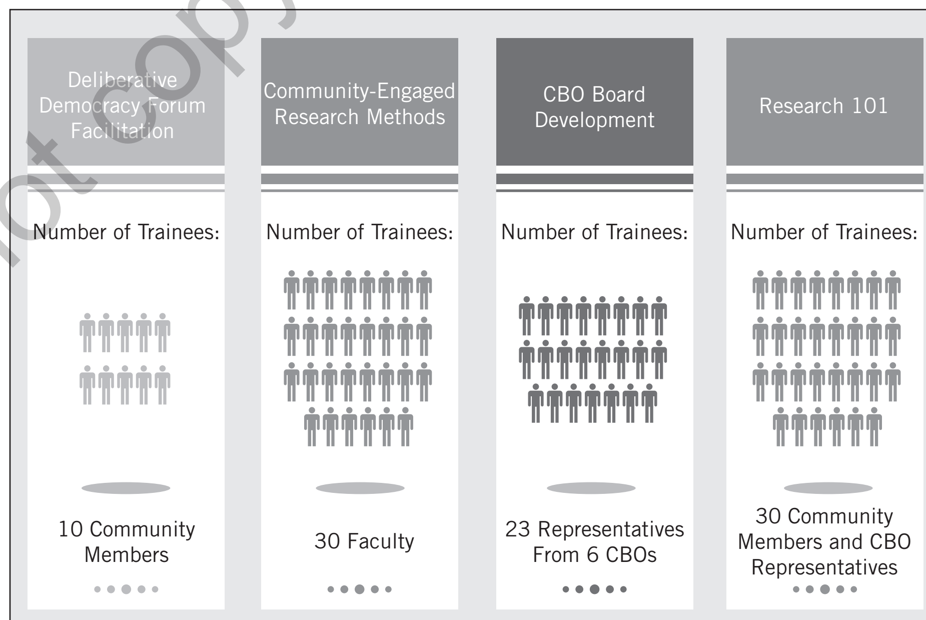
Community Capacity Building

Figure 1.2 outlines our community capacity-building activities. We held three primary activities to build community capacity to partner in research, including deliberative democracy forum facilitation, community-engaged research methods trainings for faculty, and trainings for CBO board members on board development and community members ("Research 101").

We also conducted a facilitator training in deliberative democracy forums with 10 selected leaders to prepare them to conduct community forums. In collaboration with the Center for Civic Participation in Tempe, Arizona, we held the training with the selected community members so they could conduct community forums in the style of National Issues Forums (Muse, 2009). We used LISTSERVs, English and Spanish language newspapers, and word of mouth to advertise the training opportunity. Applicants for the training sessions completed a written application in which they reflected on their desire for training, their involvement in the Riverside community, and the qualities they possessed that would make them a good facilitator. From a pool of 40 applicants, the Steering Committee selected 10 community members with whom we held interviews before accepting them into the program. Another two SC members also joined the training.

Prior to the start of the community forum facilitator training, all facilitators signed an MOU that outlined payment information and training schedules. The training consisted of two daylong, in-person sessions with professional trainers, two 2-hour practice

FIGURE 1.2 ● Capacity Building



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sessions, and two 1-hour follow up phone calls with the trainers. Over 3 months, facilitators met with the project team six times to attend instruction and practice sessions; all training activities were held on Saturdays to accommodate the facilitators. To incentivize the facilitators, we paid $150 for each daylong training, $50 for each 2-hour practice session, $25 for each 1-hour phone call, and an additional $200 for those who participated in all six activities. During practice sessions, we used published National Issues Forums guides, "Youth and violence, weighing the options: How can we encourage healthy weights among America's youth?" and "*Tensiones raciales y etnicas*," and practiced with community volunteers. Facilitators tested out their skills using these guides during two mock forums: one in English and one in Spanish.

Second, we held the "Dos and Don'ts" of Community-Engaged research with 30 UCR faculty. Developed by the University of Arkansas for Medical Sciences Translational Research Institute, this training includes simulation and role reversal, video testimonials, and group reflection and debriefing (Coffey et al., 2017). The goal is to increase researchers' understanding of CBPR and the potential points of view and experiences of CBOs and communities engaged in partnered research.

Third, we held additional trainings. One was a CBO Board Development workshop with 23 representatives from six local CBOs. This workshop focused on CBO capacity building to partner in research. Then we held "Research 101" with 30 community members, including CBO representatives. The training focused on (1) CBPR approaches and research methods (qualitative and quantitative), (2) the regulatory process (IRB approval), (3) academic-community partnerships (shared decision making and collaborative hypothesis development), (4) research implementation (training staff, study protocols, informed consent, recruitment and retention), and (5) dissemination.

Community-Led Data Collection

Through community-led data collection, we trained stakeholders to conduct research and also engaged stakeholders, both grassroots and grasstops, in research. This project was an engagement award, and the goal was to prepare community members to collect data on community health concerns, priorities, and resources. That said, we prepared the community to conduct research. For all data collection activities, community members rather than academic researchers collected the data. Data collection began with in-home meetings where community participants discussed community concerns. These were followed by a town hall meeting (a non-research activity that involved engagement of stakeholders in information sharing) in each community to disseminate findings from the neighborhood's in-home meetings. We then began the deliberative process to identify community health priorities. This process involved framing sessions and four community forums, followed by a community-wide mental health gathering.

For this project, we used the **Deliberative Democracy Forum** (DDF) method (Gastil & Levine, 2005; Naylor, Wharf-Higgins, Blair, Green, & O'Connor, 2002). The Kettering Foundation, a nonprofit organization that engages citizens in collective action, developed and refined this approach. This method follows well-established procedures to prepare for forums through naming the issue, framing sessions, facilitated forums involving deliberation or weighing the pros and cons of alternate choices, common ground (shared values), and the identification of collective and individual action (Gastil & Levine, 2005). Deliberative methods are designed to engage key stakeholders in research around shared public health concerns (Naylor et al., 2002). Figure 1.3 outlines our framework for genuine community engagement in creating a foundation for research, capacity building, and research participation.

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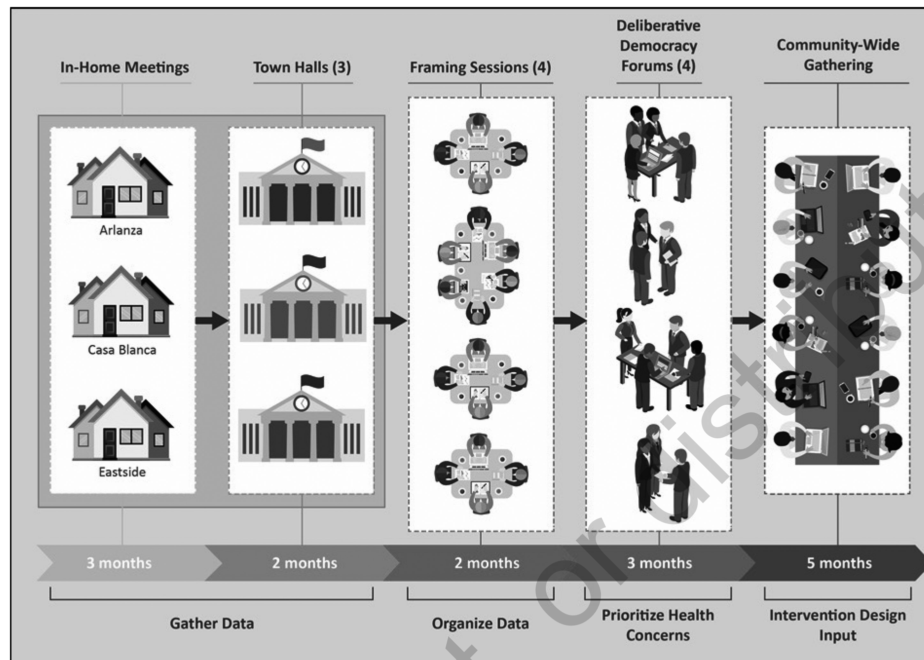
FIGURE 1.3 ● A Framework for Genuine Community Engagement



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In-Home Meetings

As a first step to engage the grassroots community in research, we held a series of in-home meetings across the three neighborhoods. The Community Investigator suggested using a method mirroring aspects of a Tupperware party—a host family invites friends, family, and neighbors to their house, the group eats together, and an outside entity presents information. In San Diego, the *Latinos y Latinas en Acción* project uses in-home meetings, akin to focus groups held in people's homes, and host families recruit participants (O'Neill et al., 2008). In collaboration with the Community Investigator, the SC community representatives identified three hosts in each of the three neighborhoods. Once identified, we provided the hosts with approximately 30 invitations and asked them to invite adults they knew to their house to participate in a discussion on health. We held discussions in English or Spanish depending on the preference of the host and attendees. We also provided each host a $100 gift card to a local grocery store for opening up their home to others and the project team.

We conducted nine 90- to 100-minute in-home meetings, four in English, four in Spanish, and one bilingual Spanish and English, and held three in each community. In-home meetings were held in host families' living rooms, outdoor patios, and driveways and included between seven and 18 participants. A total of 69 community members between the ages of 18 and 89 participated in the forums. In-home meeting attendees were predominantly Latinx (49.3%; n.b. > 25% of participants chose not to self-identify their race or ethnicity) and women (78.3%). Most were Catholic (44.9%) or nondenominational Christian (37.7%). Over one third (36.2%) reported an annual income of less than $20,000, with about one quarter (26.1%) reporting an income between $20,000 and $49,999.

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The Community Lead, with assistance from the team's qualitative expert, facilitated all in-home meetings using a semi-structured interview guide with questions intended to elicit community health concerns, priorities, and resources. We used the following question, "What are some health concerns among families in your community and neighborhood," to brainstorm health priorities and elicit single item responses (e.g., diabetes). As participants listed health concerns, the facilitator jotted them down on a large sticky note. Across the in-home meetings, this brainstorming task generated more than 65 unique items. Like terms were collapsed together resulting in a list of 48 health concerns. Table 1.1 shows the list of 48 unique items generated

TABLE 1.1 ● List of the 48 Items Generated During In-Home Meetings Within Their Categories

Group 1	Group 2	Group 3	Group 4
Mental health	*Preventing and managing chronic conditions*	*Safety*	*Access to care*
Mental health stigma	Nutrition	Resources for senior citizens	Sex education
Stress	High cholesterol	Safety as barrier	Lack of health screenings
Substance abuse	Adult obesity	Domestic violence	Lack of awareness of resources
Suicide	Diabetes	Bullying	No health insurance, undocumented status
Anxiety	Cancer	Childhood trauma	Access to health care
Depression	Kidney problems	Self-harm	Cost of prescription medications
Alzheimer's	High blood pressure	Housing	Health insurance coverage
Homelessness	Asthma	Transportation to clinics	Women's health
Dementia	Arthritis	Environmental contamination	Access to dental
Schizophrenia	Exercise	Multiple family households	Health literacy
	Chronic diseases	Safety	Unaffordable co-pays
	Access to healthy food	Childhood trauma	Underinsured
	Anemia		
	Childhood obesity		

**Please note items are not listed in any particular order.*

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during in-home meetings. These items were then used as the single items that were sorted into piles or groups during the framing sessions.

Framing Sessions

Once a list of health priorities was established, we held four framing sessions facilitated by the trained community facilitators who began each session by explaining how the 48-item list was generated (i.e., analysis of in-home meeting brainstorming data), then asked participants to sort the list of items into three to four piles or categories based on similarities and to label each pile. The 48 items were written on moveable paper with Velcro on the back and were placed on a fabric wall. As participants collectively discussed the similarities and differences among items and their placement into piles, facilitators moved them into piles on the fabric wall.

We invited diverse stakeholders to participate in the framing sessions, including in-home meeting participants, and representatives from CBOs, health care clinics, education systems, and local government. The CHC LISTSERV as well as existing partnerships and contacts in local schools, nonprofits, and city government were used to recruit participants. Framing sessions were held in one of the three communities and included a mix of stakeholders from the local Riverside area. Each session was attended by a diverse set of stakeholders; consequently, the items were sorted and named somewhat differently each time. Participants were not compensated. Refreshments or meals, depending on the time of day of the session, were provided. Table 1.2 outlines the number of framing sessions, the number of categories within which items were placed, and the label given to each category.

Overall 50 people participated in one of the four framing sessions. Participants included representatives from local CBOs, fair housing, Catholic Charities, the police department, Head Start, and parks and recreation; staff from federally qualified health care clinics, community clinics, and county public health and behavioral health programs; school teachers; environmental justice advocates; academics; and SC members.

We then used an ethnographic method, cultural domain analysis, to generate a cognitive map of stakeholders' categorization of the health priorities (Romney, Weller, & Batchelder, 1986). This method examines how members of a group who share a culture characterize aspects of that culture through a cognitive domain. The domain itself is defined by words, phrases, or concepts that conceptually symbolize a single idea. In this case, the 48 items generated during the in-home

TABLE 1.2 ● Categorization of Items by Framing Session

Framing Session	Category 1	Category 2	Category 3	Category 4
1	Mental health	Health disparities	Social justice	
2	Mental and physical health	Preventive health	Health care for all	
3	Mental health	Physical wellness	Lack of awareness and resources	
4	Mental health	Health management	Health care for all	Environmental health

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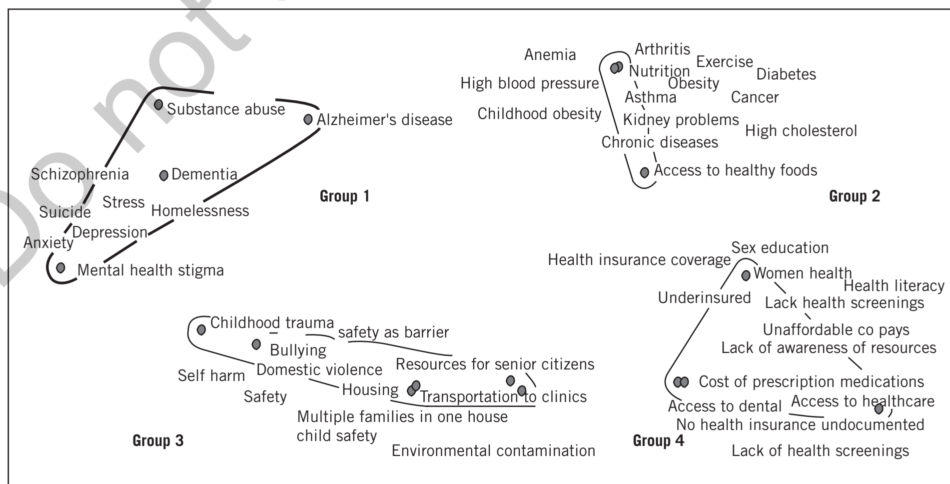
meetings served as the basis for the domain of community health priorities. We then used Anthropac, an analytic program designed to collect and analyze cultural domain data, to identify underlying relations between items and meaningful group categorizations (Analytic Technologies, 2008). Using the multidimensional scaling tool that identifies each item as a separate point on a two-dimensional map (Hout, Papesh, & Goldinger, 2013), we identified patterns in the categorization of items across the four framing sessions. The two-dimensional map spatially placed items more conceptually similar next to each other; whereas items father apart were conceptually distinct. We then conducted a cluster analysis of the multidimensional scaling to identify meaningful categories of items across the framing sessions. Analysis identified four meaningful clusters. Project team members labeled each cluster based on framing session discussions. As shown in Figure 1.4, the 48 items were sorted into four categories, including: mental health (Group 1), preventing and managing chronic health conditions (Group 2), safety (Group 3), and access to care (Group 4).

These four categories informed the issues or choices outlined in the Issue Book, which guided deliberation during the forums. Issue books include background information on the topic of deliberation and outline three or four issues or choices for discussion during deliberation. They are designed to provide forum participants with neutral and well-balanced knowledge, so they can participate in meaningful deliberation of the issues at hand (Muse, 2009). Our issue book was written by project team members with input from trained forum facilitators. Following standard guidelines, our 13-page issue book included the following key elements: a descriptive title ("Latino Health Riverside Deliberative Democracy Forums"), background information outlining health disparities experienced by Latinx communities, the LHR project including descriptions of the SC and forum facilitators, and descriptions of the four issues presented as choices for deliberation. The final page focuses on common ground by asking participants to choose only one of the four issues discussed and to discuss individual and community action needed to address the selected issue. This final activity is intended to activate the participant beyond the deliberation.

FIGURE 1.4 ● Items Sorted Within the Four Categories



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Deliberation

We conducted four 90-minute forums, two in English and two in Spanish. We held one each in Casa Blanca and the Eastside and two in Arlanza. Forums met in public spaces (e.g., community recreation centers) and included between 10 and 33 participants. With input from the Steering Committee members, we developed a postcard to recruit participants. The CHC staff disseminated the postcard electronically via the center LISTSERV and their professional networks. SC members and in-home meeting hosts also distributed the postcard through their networks.

A total of 65 community members between the ages of 18 and 68 participated in the forums. Forum attendees were predominantly Latinx (73%) and women (78%). Most were Catholic (54%) or nondenominational Christian (18%). Seventeen percent reported an annual income of less than $20,000, 28% reported between $20,000 to $49,999, 18% reported 50,000 to 74,999, and 17% reported $75,000 or more. They represented diverse backgrounds and professions, including educators, teachers, researchers, CBO representatives, parents, students, immigrants, and members of faith-based organizations. Forum attendees also included elected officials (i.e., local, county, and state political leaders), school administrators, and health care administrators. At the end of the forum, we collected data on participants' top community health priority. Across the forums, 30% indicated mental health as the most important concern for them and their family, 29% prevention and management of chronic health conditions, 20% safety, and 20% access to care.

At the beginning of forums, facilitators provided a hard-copy of the issue book to participants and verbally presented key information focusing on the four issues for deliberation. Facilitators then asked participants to weigh the pros and cons of each choice. For each choice, facilitators asked, "Why should we focus on addressing [choice] in our community? What are existing strengths and resources in our community that could be used to address [choice]? What are some of the barriers to addressing [choice] concerns as a community?" We also asked participants to prioritize the four health concerns in the issue book, which were discussed during a group discussion.

Key themes for each category emerged across the forums. For Choice 1, mental health, participants explained that stress was a root cause of depression and anxiety. For Choice 2, preventing and managing chronic health conditions, participants discussed the need for health education and information on how to better manage conditions such as diabetes and high cholesterol and blood pressure. For Choice 3, safety, participants stressed that isolation from neighbors, which was connected to not feeling safe in their neighborhoods (e.g., fear of gun shootings, violence exposure), negatively affected mental health. For Choice 4, access to care, participants indicated that lack of Spanish speaking providers, stigma, and legal status created barriers to health care service use. While community participants felt that all topics were important, when facilitators asked them to identify the topic of most importance and reach a consensus, mental health consistently emerged as the most important issue.

Mental Health Forum

Once mental health was selected as the number one issue in each of the three neighborhoods separately, we then obtained more direction from the community regarding the types of interventions they believed would be most important and effective within their communities. To do this we facilitated a mental health forum that we called a *Community-Wide Gathering on Mental Health*. A total of 83 stakeholders participated in this forum. Participants included residents of the three neighborhoods; local political leaders; college students; representatives from local churches, schools, and health care

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systems; and decision-makers from several county agencies (e.g., mental health, public health, city government). We conducted this gathering in a large space, easily accessed using public transportation, that could accommodate 16 tables with approximately five to eight persons at each table. To ensure stakeholders from diverse backgrounds were represented at each table, the community lead assigned participants to specific tables. For instance, community members from Arlanza, Casa Blanca, or Eastside, clergy, college students, health care providers, and decision makers would have been assigned to the same table so as to encourage the sharing of diverse perspectives. Of the 16 tables, four were reserved for those whose primary language was Spanish or who were bilingual English and Spanish speakers. Discussions at each table were encouraged by a trained facilitator, including those who trained in facilitation for the purposes of our earlier deliberative forums or SC members who attended a facilitator training.

To prepare for the mental health forum, we created a presentation that introduced basic information about mental health and depicted persons with specific mental health problems, which we presented in English and then in Spanish. We presented didactic information on stress and vulnerability, resilience, mental health treatments, and barriers to care such as stigma; and on commonly occurring disorders, specifically depression and anxiety disorders. We embedded videos into most sections of the presentation, including those that introduced concepts (e.g., causes of mental illness) and those that depicted specific disorders (e.g., postpartum depression). Videos showing disorders were drawn from multiple online sources, and all featured Latinx describing their experiences with a specific mental illness, usually including how they or their family members first realized they had a problem, how their illnesses influenced not only themselves but also their families, and their treatment and recovery. All videos were in either Spanish with English subtitles or English with Spanish subtitles.

Following the presentation, we introduced the concept of deliberation. We used a modified version of the Kettering Deliberative Democracy Model by emphasizing balanced and neutral presentation of information, deliberation of choices, common ground, and consensus building. However, unlike this model, we held small group discussions facilitated by trained facilitators rather than forum-wide discussions facilitated by one or two facilitators. The use of small group facilitated discussions aligns more closely with planning cells, a similar deliberative method (Caman et al., 2013). During deliberation, participants consider the pros and cons of each choice and then collectively reach consensus on how to move forward with addressing the prioritized issue.

To further prepare participants for deliberation, we held a 10-minute mock deliberation in front of the room about the following issue: “The local school has received funds for an extracurricular program. School administrators have offered two options, a new sports program or a new music program. Which should we choose?” We explained that the group would have 15 minutes to discuss the pros and cons of the two options. Then, for the next 6 minutes, they would pass around a “talking stone” so that each person had a chance to present their own ideas. Finally, for the last 6 minutes the group would attempt to reach consensus. We explained that if consensus was not reached, then each person would vote for his or her preferred option and the option with the most votes would become the priority.

After all participants had a chance to observe and ask questions about the mock deliberation exercise, we proceeded to deliberate four issues. These issues were prepared beforehand through discussions with the Steering Committee, who also reviewed and edited the descriptions provided to the participants. Briefly, the issues were:

1. Who should be our target population for mental health interventions: Choice 1 adults or Choice 2 children?

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2. What would be the best way to reduce barriers to mental health treatment: Choice 1 more community education and stigma reduction or Choice 2 programs to directly link community members with mental health services?
3. Where should mental health services be provided: Choice 1 in community settings or Choice 2 in clinics?
4. What is more important: Choice 1 preventing mental health problems or Choice 2 providing better treatment to those who already have mental health problems?

Participants at each of the 16 tables selected a spokesperson. Each of the 16 tables was assigned one of the four issues for deliberation so that at least four tables separately deliberated each issue. Brief descriptions of each issue and each option were provided. As indicated in Box 1.1, participants were asked to consider several points while discussing the pros and cons of the two assigned choices. Participants at each table proceeded though the steps of deliberation as described above. Then, spokespersons presented the results of the deliberation at their table.

There was unanimous agreement (all four tables) about the target population (participants were especially concerned about children) and reducing barriers to treatment (community education and stigma reduction were the preferred approaches). There was almost unanimous agreement (three of four tables) about where services should be offered; most agreed that services should be offered in community settings (e.g., community centers, CBO's) rather than in clinics. Regarding prevention and treatment, the opinions were evenly split, with two of four tables favoring prevention and two favoring improved treatment.

BOX 1.1 POINTS TO DISCUSS WHILE DELIBERATING THE CHOICES

- How will this affect your family, neighbors, and community?
- How many people is this likely to help?
- Who is it NOT going to help?
- How practical (easy or hard) would this be?
- How long would it take to see results?

Outcomes and Lessons Learned

A number of outcomes and lessons learned were identified over the 2 years of this engagement project. Our situation at the outset of this project was challenging in several ways. In contrast to other nearby California counties, there was no existing organization in Riverside County focused on Latinx health with whom academics could partner. In addition, we knew of no specific individual that the local Latinx communities looked up to as a health leader. Second, the academic leadership of the project were newcomers to the area and therefore unfamiliar with the local communities, foundations, and/or health and public health systems. In retrospect, we as academics may have been able to do a better job had we waited to start this project until we had developed more relationships and learned more about the local community and health services. For example, we would have been in a better position to involve more individuals with a health background on our SC.

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The success of the project's community engagement in creating a research foundation, building capacity, and grassroots and grasstops participation in research was in large part attributable to our community lead, who was willing to take on this project even though she did not have a background in health or health care. A native of Riverside, she was well known and trusted because of her prominence as an elected board member of the local community college, her role as an advisor to the UCR chancellor, and her long history of political leadership, especially concerning criminal justice issues. In short, the project benefitted tremendously from her active involvement and the trust that she had built up over many years with the local community.

Our community lead assisted in selecting and convening the SC. The SC was critical to building a foundation for partnered research. The SC provided valuable information on community engagement, especially the engagement of hard-to-reach immigrant communities in research and project activities, as well as connected us to key organizations and stakeholders throughout the city of Riverside. We learned that our commitment as project leaders and continued presence in the community furthered SC members' dedication to the project and commitment to carry out project responsibilities.

It was striking that many of the higher-level Latinx community leaders, including our community lead for this project, were quite surprised that all three local neighborhoods chose mental health as a primary concern. This illustrates that within populations—in this case the Latinx population—it is critical that community engagement efforts not only involve leadership but also make a special effort to engage grassroots residents, because they may have differing perspectives. We felt that our in-home visits were very successful in reaching the grassroots population, and we can recommend this approach for those who wish to engage with Latinx grassroots groups in particular, in part because of the strong cultural emphasis on families and homes.

One of the goals of this project was to empower local community members, and hopefully our own SC members, to move forward with a health agenda. For example, we had hoped that our SC would continue to meet regularly even though they would not be receiving compensation after the end of the project. But, as is often the case in CBPR projects (Tai-Seale, Sullivan, Cheney, Thomas, & Frosch, 2016) the shift of leadership and power from the perceived *experts* at the university to the SC or community leaders was challenging. The SC did not continue to meet. This could be because we focused on capacity to partner in research and not leadership skill development. Our focus on partnering rather than leading may have inadvertently positioned SC members to see their role as solely advisory and not as leaders able to continue the work post funding. This could also have been because only a few members of the committee were current residents of the three neighborhoods. The current residents included two undergraduate students and an older retiree. More established residents with strong current community connections and influence may have been more motivated to organize and take action independent of the project and outside of the meetings.

Furthermore, while the monthly involvement of SC members in the project was critical to building a foundation for partnered research, maintaining this group involved time-consuming administrative tasks. For instance, for each SC meeting, staff from the CHC at UCR identified the location for the meeting and corresponded with the location's point person; they also ordered and picked up or coordinated the delivery of food. Staff also took minutes and printed material for the meetings. The university, in effect, supported these administrative and logistic services in kind. This infrastructure did not continue past the end of the funding, in part because two

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of the academic leads for the project left the university. We recommend that those who engage in CBPR projects keep in mind, and budget for, the often significant administrative infrastructure required to ensure running projects and meetings smoothly. Furthermore, it could be helpful to have more participation of SC members in these administrative tasks, including taking minutes and liaising between the committee and project team, which can foster a sense of ownership and potentially develop leadership skills. Regardless of whether the administrative responsibilities are borne by the university-based project staff, by community members, or are shared, funding should be allotted to support these activities.

Our second goal was to build stakeholder capacity to engage in partnered research. We engaged approximately 385 unique stakeholders in either engagement or research activities through trainings, in-home meetings, framing sessions, deliberative democracy forums, and the mental health forum. Furthermore, we trained 10 individuals to facilitate Deliberative Democracy Forums. We found that our strongest facilitators included a high school teacher and an activist, both of whom lived and worked in the neighborhood where they conducted forums. While the skills facilitators developed through the training were uneven, all improved their public speaking and gained knowledge of community forums. We felt that the experience of training in leading deliberative democracy meetings was particularly valuable for community members. Since many trainees were young, they learned facilitation and leadership skills that are generalizable to many settings and will likely help them for many years to come.

Our third goal was to identify priority health concerns in Riverside Latinx neighborhoods. By using methods to obtain grassroots perspectives of community health needs and methods to engage diverse stakeholders, including grasstops, we were able to bring community needs to public discussion and deliberation (Cheney et al., 2018). We did this by holding both in-home meetings with grassroots community members and deliberative forums with diverse stakeholders including both grassroots and grasstops. However, we would like to note that while community forums can be large gatherings, deliberation typically works best with fewer than 15 people. Several of our forums included more than 15 participants. This experience taught us that if the purpose of a community forum is to deliberate, then it needs to be small. Or, alternatively, smaller deliberation groups can be formed within a larger group, as we did in our final mental health forum.

Conclusion and Outcomes

Through this engagement project, we built academic and community partnerships with diverse stakeholders and engaged the Latinx community in prioritizing health. We engaged over 90 individuals through our capacity building and training activities alone. We also identified four community health priorities (mental health, access to health care, management of chronic health conditions, and neighborhood safety) across the three predominantly Latinx neighborhoods and then asked the community to identify the primary health priority.

We thought that the in-home meeting model was particularly effective in obtaining the point of view of grassroots community members and that the facilitation training likely conveyed skills to trainees that they may find useful over their lifetimes. In addition, over the process of this project we learned about several existing mental health programs that were not widely known among our participants, and we were able to provide more information about these resources to the community.

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We were disappointed that we were not more successful in creating follow-up and continuing partnered research projects. This was in part because two of the lead academics left the CHC and the university. At the same time, we have been able to facilitate at least one large NIMH–funded research project involving local churches, initiated by colleagues at Rand Corporation, Santa Monica. In addition, other academics based at the CHC have continued their involvement with Latinx communities. As summarized above, we emerged from the project with direction from the community that could serve as an excellent foundation for future research. Community members were most concerned about mental health of *children*, wanted to see more services delivered *in communities*, and believed that a strong emphasis should be placed on *community education* about mental health and mental health treatment, particularly in an effort to reduce stigma.

By the end of the project, we had a very strong and committed Steering Committee. While we, as the community academic partnership, had intended for the community to use our work as a foundation to further Latinx health issues, this did not happen. We do not consider ourselves as having been successful in transferring ownership of this project to the local community so that they might move forward with their own agenda. From our discussions with community and SC members, we understood that they anticipated the project would result in change. Community members may feel disappointed that the project did not have the full impact that they had hoped for or expected—a well-known risk and concern for all community-engaged work. However, we did disseminate the findings broadly throughout the Riverside community.

Perhaps the greatest contribution of this project was raising the general awareness of the importance of mental health issues within local Latinx communities. We made presentations to local government groups, such as the Riverside City Council, local churches, and community networks and organizations. We do know that the finding of mental health as the top priority among the participating Latinx neighborhoods surprised many leaders and influenced several local programs. For instance, a local CBO used project findings to inform their strategic plans and expand their mental health services. It was our impression that our dissemination activities opened many new conversations with government leaders and community health systems and certainly turned attention toward mental health as a major concern within Riverside's Latinx communities. Additionally, we were able to provide information about mental health resources to the community.

Overall, our work points to the need for a framework of engagement, such as the one followed in our project, to carry out longer-term initiatives involving multiple stages.

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Resources

Anthropac, Analytic Technologies, 2008
http://www.analytictech.com/anthropac/anthropac.htm

Center for Healthy Communities
https://healthycommunities.ucr.edu/

The Kettering Foundation
https://www.kettering.org/

National Issues Forums
https://www.nifi.org/

Discussion Questions

1. The chapter title refers to *grassroots* and *grasstops*. What is the significance of these terms for this project? How do they relate to the engagement framework outlined in the chapter? How did this approach impact project outcomes?
2. This project was conducted with Latinx communities in California. Do you think the method appeared to be well suited to engage this population? Why or why not?
3. Describe another community with whom this method could be conducted. What makes it a good fit?
4. The authors note that the project did not continue after the funding period ended. What were some factors that may have affected sustainability? What recommendations would you make to improve sustainability in a future project?

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