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### Con Confianza: Using Community-Based Participatory Research Principles to Inform Community-Academic Partnership Practices and Build Trust in Hispanic Communities

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***Con Confianza: Using Community-Based Participatory Research Principles to Inform Community-Academic Partnership Practices and Build Trust in Hispanic Communities***

by Sharon Tafolla

A Capstone Project submitted in partial fulfillment of the requirement for the degree of Master of  
Public Health

University of San Francisco

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### **Abstract**

Hispanic communities are at disproportionate risk for chronic diseases and researchers have cited the need for further community and culturally informed studies to improve research outcomes to either make treatments and interventions more generalizable or modify them to the needs of Hispanic communities. However, many of the same linguistic and cultural barriers to health care access and utilization also impact the ability for Hispanic groups to participate in research studies. Community Academic Partnerships (CAPs) are positioned to conduct culturally and linguistically competent research in Hispanic communities. For research in Hispanic communities to be effective, CAPs must prioritize practices that build and maintain trust. This can be done by applying the most common and sustainable practices in successful CAPs informed by Community Based Participatory Research (CBPR) principles. These include establishing a role and definition of the community; including the community in the design process; ensuring ongoing knowledge transfer among academic leaders and community members of the community and the subject matter researched; and performing ongoing assessment of community engagement across the continuum of community engagement. These practices communicate commitment to Hispanic communities in CAPs and also provide academic researchers accountability measures ensure the partnership is reflective of the community needs. These practices also contribute to the building and maintenance of trust and a sustained partnership.

*Keywords:* Community-academic partnerships, academic community partnerships, community based participatory research, CBPR, community based participatory research principles, Hispanic communities, trust, Hispanic health outcomes, Latino communities, Latino health outcomes.

Building and Maintaining Trust: Best Community-Based Participatory Research Principles to Inform Community-Academic Partnerships in Hispanic Communities

**Introduction**

The Centers for Disease Control and Prevention (CDC) data from 2017 noted Hispanic/Latino population groups are at a disproportionate risk for mortality from chronic health conditions and diseases, including cancer, diabetes, and kidney disease (CDC, 2020). Death from these conditions is preventable, and can be controlled, with early diagnosis, existing treatments, or interventions. Hispanic adults are more likely to have uncontrolled blood pressure and blood sugar levels, and faster progression to end stage renal disease diagnosis (Escarce, 2006; Desai, 2019). Hispanic communities face various healthcare and societal challenges that are common barriers to accessing and utilizing preventive services. However, there are also gaps in understanding how treatments and interventions are accessed and utilized within Hispanic communities that have diverse sub-ethnicity groups (e.g. Mexican, Puerto Rican, Cuban, etc.). In addition to considering the various important individual and social factors such as personal beliefs, cultural values, education, income, immigration status, and acculturation, studies have cited the need for more community-informed trials and pilots for treatments and interventions that can improve healthcare access, adherence, and utilization among Hispanic communities while addressing differences between their sub-ethnic groups.

Similar to barriers in access and utilization, there are also various socio-cultural and socio-economic barriers that impact Hispanic community participation in research studies. Inclusion and participation by Hispanic communities in research studies is needed to have

community-informed treatment and interventions that are reflective of the community needs and responsive to individual and social factors that inhibit or enable effectiveness. For purposes of consistency, this paper will use ‘Hispanic’ to represent those who identify as Hispanic or Latino.

Community-Academic Partnerships (CAPs) have provided a key role in increasing knowledge on more community-informed, evidence-based treatments and interventions that have had promising results for addressing disparities in health outcomes among historically underrepresented communities, including Hispanic population groups. The most common CAPs in Hispanic communities are informed by Community-Based Participatory Research (CBPR) principles. Israel (1998) identifies the core CBPR principles, which include a commitment to: building upon community strengths, fostering co-learning and capacity building, and balancing research and action for mutual benefit of all partners. Trust and respect, both important cultural values of Hispanic communities, can also be built and maintained by prioritizing sustainable community engagement practices informed by CBPR principles. Sustainable community engagement practices can strengthen future research planning and subsequent research outcomes in studies for interventions or treatments that are intended to address health disparities among Hispanic communities.

## **Background**

### **Health Outcomes in Hispanic Communities**

The most common chronic conditions reported among Hispanic populations include diabetes, high blood pressure/stroke, cancer, and heart disease/heart attack (Saulsberry, 2016). An analysis of the U.S. National Health and Nutrition Examination Surveys between 2011-2016 showed that the Hispanic population had a diabetes prevalence of 22.1 percent compared to 20.4

and 12.1 percent in non-Hispanic Black and in non-Hispanic White population groups, respectively. This included self-reported diabetes diagnosis, and undiagnosed diabetes and prediabetes based on Hemoglobin A1C, fasting plasma glucose, and 2-hour plasma glucose. Hispanic populations also had the highest prevalence of undiagnosed diabetes at 5.7 percent compared to 4.3 percent in non-Hispanic whites and 4.6 percent in non-Hispanic black (Cheng, 2016). Diagnosis is widely considered standard in preventative primary care, so it is significant that Hispanics are more likely than other racial ethnic groups to have undiagnosed diabetes and prediabetes diagnosis.

There are also significant differences that need to be accounted for within Hispanic ethnicity sub-groups. For example, for diabetes, Mexican sub-ethnic groups had the highest prevalence at 24.0 percent and was followed by a prevalence of 19.8 and 19.3 percent in Puerto Rican, and Cuban/Dominicans, respectively (Cheng, 2016). In looking at the prevalence of end stage renal diagnoses across racial ethnic groups, Hispanic population groups had a faster progression to chronic kidney disease. Researchers noted that further studies are needed to understand the impacts of socio-cultural factors, such as acculturation, against clinical outcomes that can show impacts to quality of life and disease progression (Desai, 2019).

By July 2020, the non-white Hispanic population made up the majority of COVID-19 cases and deaths for groups under the age of 50 years old, and the majority of COVID-19 deaths in the US, followed by non-Hispanic Black population groups (CDC, 2020). Although COVID-19 has spread across all socioeconomic groups, it has been noted that those with preexisting conditions, such as diabetes, are at high risk for worsened outcomes. Additional research is needed to improve chronic disease health outcomes so that racial and ethnic populations are not at a disproportionate risk of infectious diseases.

**Barriers to Health Treatment and Interventions**

Disproportionate health risks are a problem for the Hispanic community, but also for other underrepresented populations that face similar socioeconomic disadvantages and health conditions. These disadvantages and conditions can be attributed to the environments in which these populations live and work. Hispanic communities and other underrepresented population groups can also face similar challenges to receive and access appropriate health care. The Patient Protection and Affordable Care Act (ACA) made significant progress in increasing the number of individuals with access to health care, but this has not been the same experience in states that did not expand Medicaid as part of the ACA (Velasco-Mondragon, 2016). Medicaid is a social welfare program that provides free or low-cost healthcare coverage, that includes preventative services, to individuals with income levels below the federal poverty level (Velasco-Mondragon, 2016). In 2014, 23.6% of the Hispanic population were living below the poverty level and would have qualified for Medicaid if eligibility and access was the sole eligibility factor (Velasco-Mondragon, 2016).

Although there is decreased mortality in the U.S. among Hispanics in comparison to non-Hispanic Black and White populations groups, there is increased morbidity due to lack of access to and use of preventative services (Velasco-Mondragon, 2016). Among Hispanic, and Non-Hispanic Black, populations living in poverty, more than half have difficulties financing drug prescriptions and accessing health services (Slausberg, 2016). In the U.S., medical expenses among diabetics have been 2.3 times higher than those considered healthy (Velasco-Mondragon, 2016). The CDC identified the excess medical costs for persons associated with diabetes was reported to be \$9,601 per person in 2017 (CDC, 2020). Delayed preventive services and lack of adherence to treatment can result in worsened outcomes and increased long-term healthcare costs

since treatment in urgent care and emergency settings can be more costly than the use of preventative services.

The cost of morbidity from a lack of access and utilization can also impact the livelihood of healthy family members when considering the tight-knit family structures in Hispanic culture. Multigenerational households are common among the Hispanic population in the U.S. This is attributed to strong family values that can be a source of emotional and financial support (Escarce, 2006). These family structures have proven to be beneficial in birth outcomes among Hispanic women (Velasco-Mondragon, 2016). However, increased wealth gaps can also be created if younger family members take on caretaker roles for others within the same multigenerational household since they usually require a dedication of emotional or financial support.

Aside from cost, there are also literacy and cultural barriers despite laws requiring health care providers to offer language translation and interpretation services. The majority of Hispanic communities are predominantly Spanish speaking, have limited abilities to speak or understand English. Hispanic populations have shown adherence to health recommendations and noted increased satisfaction to health providers who speak Spanish (Velasco-Mondragon, 2016). Health and social programs that lack quality translator services need to ensure patients have access to information that is culturally relevant or within their literacy level. If translations are not clear, or if interpretation services are not seamless, this can lead to frustration and an unpleasant patient experience. These factors alone or in combination make it difficult and often ineffective for individuals to seek care or adhere to treatment (Goldfinger, 2012).

A small cohort study that sought to understand and identify the factors that influence type II diabetes self-management among Hispanic immigrants highlighted the barriers noted above.

Among the primary factors impacting self-management were 1) poor interactions with health care providers where they lacked health education and information on the disease, 2) clear information on what some of the nutrition terminology meant such as ‘low carbohydrates’ due to language and cultural barriers, and 3) financial constraints to follow medication regimens due to lack of health insurance and unpredictable income (Smith-Miller, 2017). This study is not generalizable to all immigrant or racial ethnic populations, or even all Hispanic populations as differences exist within subgroups; however, the language and access barriers can be experienced in other racial ethnic communities where English isn’t the primary language and there are financial barriers to accessing healthcare.

In contrast, a study on the effectiveness of using Spanish-speaking cultural community health workers showed a decrease in blood sugar levels and mental distress from diabetes among participants due to catered health education on diabetes and self-management techniques (Spencer, 2018). This gives evidence to the need for treatments and interventions that cater to the cultural and linguistic needs of the target population, including more Spanish speaking providers and professionals.

### **Culturally Informed Evidence Based Interventions and Treatments**

To address issues, such as access to, and utilization of health care services and treatment adherences, we must identify solutions that simultaneously target the specific behaviors and facilitate use for the population groups of focus. However, many studies are challenged by reduced participation from racial ethnic communities. Studies have noted that improved participation in research from diverse racial and ethnic populations can enable the development of generalized medical and clinical interventions or their modifications (Cunningham-Erves, 2020).

Escarce (2006) identifies that the lack of evidence-based or evidence-informed practices (EBP/EIP) are due to lack of evaluations for interventions that have been implemented in Hispanic communities. These cultural factors can include protective health behaviors seen among recently migrated Hispanic teens who lack acculturation and eat less fast food, or even the increased family support that has been identified as a driver of positive birth outcomes among Hispanic women (Escarce, 2006). Cultural factors influencing the implementation and outcomes of interventions in underrepresented communities might be difficult to observe without a culturally competent evaluation. This presents an opportunity for academic institutions to be a part of the solution since they have access to structured evaluation systems and may have proximity to communities with lived experience depending on geographic location. Academic settings can conduct evaluations of implemented community interventions and add to the knowledge base for evidence-based interventions (EBIs).

There are also some factors within academia that can contribute to the lack of EBPs/EBIs, primarily a lack of representation in academia. The lack of research opportunities in racial and ethnic communities can be from a lack of diversity in academic and research settings. Additionally, a study where there is interest in studying racial ethnic communities can have poor research participation if there is poor research design that does not account for the specific lived experiences or research interests of the community (Minkler, 2004). This could be characterized in the scenario where a researcher wanted to study Hispanic health behaviors in migrant populations but is not familiar with the community context, including housing settings, healthcare limitations, or working conditions. This can possibly be attributed to the same or similar root causes from the cultural and linguistic barriers encountered in healthcare systems.

### **History of Research in Racial Ethnic Communities**

Participation in research from racial ethnic communities has been shown to be influenced by mistrust rooted from historical events in health systems and discriminatory experiences in healthcare settings. In the Black community, the Tuskegee Syphilis study is widely cited across various socio-economic groups as a reason for mistrust of academic research settings and health care systems. Other factors that promote lack of participation in research studies in Black communities include perceived racism and discrimination, and a lack of adequate information regarding the study/research (Scharff, 2010). For example, this could result from how researchers initially approach a community and how transparent they are with the purpose of the study, or in communicating the findings from the study.

Socio-political historical events in Hispanic communities have been identified to influence trust include fear of immigration, anti-immigrant sentiments, and racism and discrimination; similar to the factors identified by Black communities (Moore de Peralta, 2020). Other factors that influence lack of research in Hispanic communities have included lack of adequate information on research and study awareness (Scharf, 2010; London, 2015). Aside from these reasons that contribute to lack of participation, there is interest cited among Hispanic communities, and other racial ethnic groups, that they would like to participate in more studies to improve outcomes for their communities (Scharf, 2010; London, 2015; Mendez-Luck, 2011). Mendez-Luck (2011) cited the findings from other studies as the basis for an analysis on effective research recruitment strategies in Hispanic communities for a caregiver study, and found success in partnering with local Community-Based Organizations (CBOs) and associations for an Alzheimer's study.

### **Trust in Hispanic Communities**

Trust is important in Hispanic communities as this links to the cultural value of respect. The dynamics of trust are one of the most important in Hispanic communities due to the history of fractured relationships and lack of opportunity that feed mistrust. A huge proportion of Hispanics in the U.S. are undocumented or have a family member who is undocumented and therefore this contributes to a lack of trust in connecting with others outside of their family or close social ties (Sankaré , 2015). This distrust can transfer to their perception of research and skepticism with sharing their private or health related information (Dave, 2018). The distrust of research institutions and health care systems from most ethnic communities also stems from a lack of representation within organizations and systems. As of 2016, Only 5% of Hispanic/Latinos have completed a graduate education or higher, meaning the representation among researchers conducting studies is minimal and academic representatives in CAPs very rarely include researchers from these communities to create positive social ties within the community of interest (i.e. Hispanic, Latino) (Schak, 2017).

The racial tensions in 2020 have also called for increase diversity, equity, and inclusion in private and public institutions. There is hope that with time there will be increased representation in academic research. Not only in those conducting the research, but also those participating.

Trust also has a valuable role in the larger Hispanic community culturally. Hispanic communities are predominantly composed of close-knit families/social ties. Individuals and families who live in isolation or far away from their families due to migration also tend to find community in the places they live or work. Individuals are challenged with their daily demands and have limited time to dedicate to something they cannot connect with so there must be an

existing network or form of trust pre-established for them to engage in other activities, such as research (Christopher, 2008; Sankaré, 2015). During recruitment and outreach, academics should know the community context and make it easy for partners in Hispanic communities to understand and provide feedback on how they are part of the solution and the long-term goals, otherwise this can hinder their engagement in research (Sankaré, 2015).

### **The Role of Community Academic Partnerships**

The CAP provides academics an opportunity to engage and include communities in the research process in varying degrees to obtain input from communities primarily impacted by research outcomes (Aisenberg, 2012). The role of the academic institution is to provide a framework and tools to complete research, and in most cases provide a source of funding to study an issue or intervention within a specific community or population. Community partners can include a community association, coalition, individual or network of community health workers, CBOs, or clinic, members or representatives from local government agencies, or even individual community members. The role of the community partners is to provide firsthand knowledge and insight of the community of interest in research or any activities within the partnership. The degree of involvement of the community partners in the research design, the study itself, and the analysis can vary depending on the objective of the researcher and the academic institution.

### **Community Academic Partnerships and Health Disparities Research**

The complementary roles between the knowledge and skills of community and academic partners in CAPs have shown to be an effective way to study treatments and interventions that seek to address health disparities (Israel, 2010). This is because solutions that address health disparities require an understanding of the cultural backgrounds and social contexts of

communities of interest (Moore de Peralta, 2020). This includes understanding where people live, work, and socialize, and the behavioral interactions that take place within these ecosystems. In the last decade, there has been an increased interest and shared knowledge on health equity, health disparities, health inequities, and the increased identification of socio-economic data from more transparent data sharing practices for race, ethnicity, poverty, and housing data. This increased knowledge and awareness has led to organizational changes in public institutions, including establishment of offices or programs dedicated to Health Equity; increased attention to the difference life expectancy between zip codes; and increase in funding to address health equity. Initiatives in academic, governmental, and clinical settings are increasingly seeking to address health disparities and advance health equity within their organizations and strategic planning (National Academies of Sciences, Engineering, and Medicine, 2017). However, it has become evident during the COVID-19 pandemic, and recent social unrest from systemic racism, that current solutions and treatments in our health and social services systems need to be further studied to understand how they perpetuate and advance disparities among racial and ethnic minorities. CAPs are in a unique position to complete research that is objective, evidence-based, and dually community centered and community-informed, and move towards health equity.

### **Challenges in Community Academic Partnerships**

CAPs are typically the ideal foundation to design and foster research that is community-based. However, studies can be labeled as ‘community-based’ but not include thorough community engagement. This could happen in any research setting whether experimental, clinical, or epidemiologic. In a study on community perspectives of community-research partnerships among ethnically diverse neighborhoods in Central and Southeast Seattle, community members reported that their interests were ignored and/or that only researchers

benefited from these partnerships, citing previous studies that only included community members to meet funding requirements, or the lack of direct benefits or compensation to participants (Koné, 2000). One-directional research approaches can leave the community members feeling used due to the lack of deliverables or improvements to the community, and further impact participation in future studies.

Community academic partners can also risk not having the right partners. The partners must know the community well and have a relationship of trust with the community, otherwise this can impact recruitment and retention of participants (Drahota, 2016). The network of the community partner and the academic partner are also important and can influence community perception. In a study on recruitment methods in East Los Angeles, the most successful recruitment approaches resulted from CBO events, CBO direct referrals, and through study participant referrals. The authors cited study participant referrals, also known as snowball sampling, as an effective sampling method in communities where there may be limited access to social or medical services and greater reliance on established community networks to get the word out (Mendez-Luck, 2011).

### **Community-Based Participatory Research Principles**

Academic institutions engaging in CAPs can strengthen the outcomes of their research in marginalized communities by adopting CBPR principles (Aisenberg, 2012). CBPR principles include: recognizing community identity; building on strengths and resources within the community; facilitating collaborative partnerships in all phases of the research; integrating knowledge and action for mutual benefit of all partners; promoting a co-learning and empowering process that attends to social inequities; involving a cyclical and iterative process; addressing health from both positive and ecological perspectives; and disseminating findings and

knowledge gained to all partners. Some studies that adopted CBPR principles have seen increased retention, positive community feedback, and better research outcomes than expected (Israel, 2005; Garcia-Rivera, 2017).

CBPR is a preferred research approach when there is a policy issue that requires community building and organization (Israel, 2010). This can include increased community empowerment, and knowledge sharing on how to engage policymakers for policy advocacy. This has been successful in CAPs seeking to address environmental health issues in marginalized communities where various CBPR principles are adopted into CAP practices.

When researchers in CAPs are not seeking to fully adopt all aspects of a CBPR approach, they should consider using CBPR principles to inform how they engage the community, ensure their research is community-informed, and establish mutually beneficial relationships. This could be helpful in a new CAP where the issues within a community are not thoroughly known or specific, and objectives are unclear, but there is intent to establish and build a partnership in the long-term. It can also be helpful in CAPs with interest in understanding solutions that work for and within Hispanic communities. This is because many principles are conducive to building trust and respect among academic and community partners, and trust is central to Hispanic participation in research and intervention implementations.

### **Recommendations**

In using CAPs and looking to establish and maintain trust, there are practices that can be implemented and informed by CBPR principles to ensure community engagement actively fosters trust in Hispanic communities. A review of the most common practices in four CAPs with Hispanic communities, CAPs covered CBPR principles shown in Table 1. Based on this

review CAPs should look to the five common practices and activities to inform and guide their partnership. First, CAPs should be transparent regarding the definition and role of the community in any engaged research. Second, CAPs should build upon community resources. Third, the community should be part of and inform the research design. Fourth, there should be processes established that ensure consistent knowledge transfer between CAP participants or leaders in the community, and the study subject matter. Lastly, there should be an ongoing assessment and measurement of progress on community engagement as an iterative form of evaluation.

**Table 1.**

*CBPR Principles Applied or Identified Across Best Practices and Recommendations by Study*

CBPR Principles	Best Practices and Recommendations by Study			
	Moore de Peralta, et al., 2020	Aisenberg, 2012	Garcia-Rivera, 2017	Askari, 2018
<b>Recognizes Community as a unit of identity</b>		-Met with community members to identify context		-Established the role Nuestra Casa would play in the partnership -Hosted trust building and conceptualization meetings
<b>Builds on strengths and resources within the community.</b>	-Engaged stakeholders at various stages -Used CHWs to provide feedback at pilot test and refinement -Trained volunteer CHW to	-Hired part-time bilingual recruiters and therapists from the local community and existing clinic staff.	-Used as a teaching opportunity for medical students	-Identified existing resources within Nuestra Casa

CBPR Principles	Best Practices and Recommendations by Study			
	conduct interview to org partners			
<b>Facilitates collaborative partnerships in all phases of the research</b>	-Developed a plan that included PASO leadership and CHWs in decision-making and research design	-Collaborated on publication and grant writing	-Collaborated on a community-wide survey to assess community needs	-Partnered with a known community leader to plan and register community for trainings
<b>Integrates knowledge and action for mutual benefit of all partners</b>		-Integrated need for depression services into mental health study		-Identified the need for the adaptation of a training to be specific to Latino community
<b>Promotes co-learning and empowering process that attends to social inequalities</b>	-Academic and community partners were co-responsible for study design, implementation, and data-analysis that focused on synergy and co-learning		-Established CPR and first-aid certification for community volunteers	-Used <i>promotoras</i> to lead trainings for other community members
<b>Involves a cyclical and iterative process</b>		-Adapted study as stakeholder feedback was received, including by participating primary care providers		-Trainings and materials continue to be updated
<b>Addresses health from both positive and ecological perspectives</b>		-Provided mental health services along with study	-Provides health screenings and care to	

CBPR Principles	Best Practices and Recommendations by Study			
			community members through a school bases health clinic	
<b>Disseminates findings and knowledge gained to all partners</b>	-Sharing study result and collecting participants' input through community forums	-Co-presented findings with community members		-Shared findings with neighboring communities and aging commissions

*Community Role and Definition*

A comprehensive plan to establish and maintain trust in CAPs will include the initial ground setting that includes shared definitions in addition to establishing a partnership agreement. Both partners should strive to identify a shared understanding of the historical and cultural context for the community of interest. This can be done by having kick-off meetings with the partnership members that include identification of everyone’s role in the community or academic institution and what they bring to the partnership.

There also needs to be a definition established for the community to create a unit of identity. One-on-one meetings with the community may also be used to find out more about what previous engagement looked like and how it has impacted the community. In a study with rural farmworkers in Yakima Washington, an investigator discovered rapport needed to be built after community members identified previous research in the community did not leave tangible benefits and the community felt the data were oppressive and not mutually beneficial (Aisenberg, 2012). This process also can serve as a validation of having selected the appropriate partner that understands the community’s history with academic/research institutions, and socio-political

influences on community members, and any countries of origins. Soon after identification, academics should seek to address and fill the gaps identified early into the process.

### *Building Upon Community Resources*

If there are gaps identified, partners should build from within the community and their networks to identify additional participants that meet the needs of the CAP. If a research design or intervention is health focused, it should see to increase the recruitment of Spanish speaking providers or other healthcare professionals that can also provide diagnosis and treatments. This can be done by identifying professionals from within the community rather than bringing in external resources. A successful practice in Hispanic communities that is not perceived as sustainable in most cases, but can be a goal for CAPs, is to include the use of community health workers, also known as *promotoras de salud*. Hispanic communities are more receptive to increased face-to-face interactions either through one-on-one interviews or discussions, or in recruitment through word of mouth in community settings (Askari, 2018). *Promotoras de salud* are specialized in community health education and are focused on cultural and linguistic competency (Askari, 2018). This can also be done through ‘train-the-trainer’ models where community members, caretakers, or youth can be trained to provide the health education services or expand trainings.

### *Community-Informed Research Design*

Among the most successful CAPs for children’s environmental health that applied all or some CBPR principles the community members were a part of the research design or policy making process (Israel, 2005). If the design was an educational tool or presentation, community members can provide input on the need for additional definitions of unknown terms. This can be done by creating opportunities or tools to share research materials and obtain input from

community members, most commonly through pilot or focus groups. The process must be iterative and show community members that their input is being applied and is welcome at any time.

### *Ongoing Knowledge Transfer of Community and Subject Matter*

Trust building requires transparent communication on the community role and definition, as well as the subject matter of the study. Since there are often various partners in the academic setting or they can often rotate, it is important to include knowledge transfer of the community background and definition established initially. This should be documented and accessible to ensure there is knowledge transfer for new community members. Additionally, as new community partners join, resources should be available to ensure they can be up to date on the subject matter the partnership is focused on or the research study or studies. Community partners feel more invested when there is shared knowledge and understanding.

For example, in the development of a culturally competent clinical cancer trial, participants were able to vocalize the need for more information on cancer and the clinical trial process. This also enhanced informed consent and the ability for community members to engage and continue participating in research (Cunningham-Erves, 2020). This can be both empowering and educational on research practices and what to expect from a study.

### *Ongoing Community Engagement Assessment*

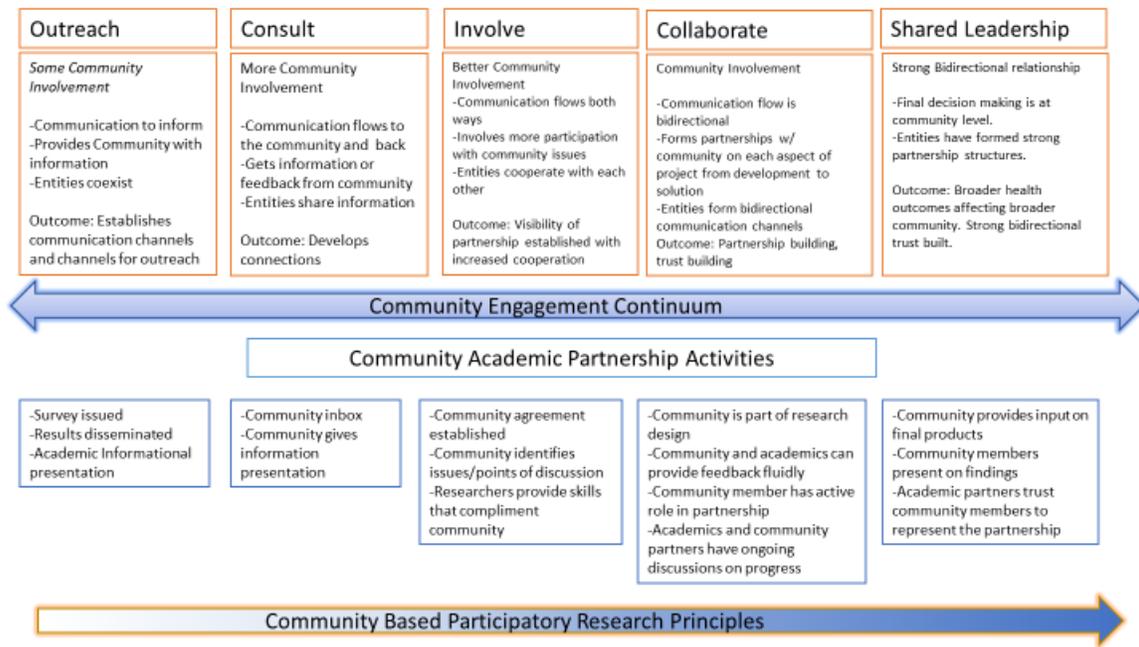
There should also be an emphasis on practices for being transparent regarding the degree of community engagement and partnership (Spears Johnson, 2016). Community engaged research that only does ‘outreach,’ and doesn’t look to provide leadership or growth to communities can cause more harm to the community and risk future trust building.

The community engagement continuum was developed by the International Association of Public Participation and has been modified by various entities, including the Agency for Toxic Substances and Disease Registry, as a framework for community engagement for health promotion and research (ASTDR, 2015). The community engagement continuum includes five different phases that researchers would progressively follow from left to right in different stages of community engagement and can be used as a tool for evaluation. The continuum begins with outreach and then consultation. Both initial stages have some community involvement, with outreach being more one-directional, and consultation including a feedback loop, but both still in place where the community is providing information that is beneficial to the researcher. The third phase is involvement, and this includes participatory communication with increased collaboration among community partners and researchers where the community partners have more involvement in community issues. The fourth phase is collaboration, and this includes bidirectional communication flow within each aspect of the project development and communication channels. Trust and partnership are built in this phase with bidirectional development and communication roles. The fifth phase is shared leadership and is similar as collaboration when it comes to communication, but it includes final decision-making at the community level. The final phase is characterized by a shared interest in the overall health of the community and there is a strong trust built where community member decisions are trusted, and the community members trust the researcher's values and respect their decisions. There can be respect throughout all these phases, but trust is not easily established until there is progression in the later phases.

Figure 1 shows the community engagement continuum alongside various CAP activities. The figure also show how these activities fall within the goal of CBPR principles.

**Figure 1.**

*Community Academic Partnership Activities Across the Community Engagement Continuum*



*Notes: The Community Engagement Continuum and the content in five phases was from CTSA’s adaptation from the International Association of Public Participation. The Community Academic Partnership Activities and placement across the Continuum were identified through the various studies cited.*

Sustainability measures that are typically seen in the collaboration and shared leadership phases are important even if researchers do not plan on applying all CBPR principles. This is because community engagement that doesn’t seek to reach full ‘collaboration’ or ‘shared leadership’ can be perceived as more harmful than good, and as noted above, can have a long standing effect on a communities perception of research and academic institutions.

There are additional factors that must also be considered and can be further analyzed to determine how they promote or hinder sustainability efforts. One of these factors includes

identifying community partners that do not reinforce power structures that can help academics avoid harm and the ability to move forward on the continuum. As highlighted in the collaborative process, the various stages of research, or even within different sub-research projects, there should be an evaluation of community engagement and a measurement of where these fall within the continuum.

The benefits of continued, reciprocal community engagement assessment could help foster the ongoing collaboration and provide accountability for the partnership and decision making that would have otherwise been established in a shared leadership phase. This continuous assessment is important in not basing progress on initial engagement but rather sustainable engagement that is built on commitment from researchers to not stop at one-directional phases. Furthermore, it presents an opportunity to hold new internal and external partners accountable by consistently assessing what went wrong and what can be built upon. By establishing an evaluation as a form of sustainability, this can make non-CBPR CAPs align with the process of building and maintaining trust with the Hispanic community. The process for building trust has been identified in previous studies to be slow and long (Moore de Peralta, 2020). It is likely this is the reflection of how much the Hispanic community values trust, and additionally respect, and how long it takes to build up these values.

### **Other CBPR informed practices**

When possible, it is always best to provide compensation, so individuals know that their time and input are valued. For example, researchers at Stanford partnered with a trusted local community agency to pilot a program that resulted in increased dementia awareness among local *promotoras* (Askari, 2018). The researchers used the partnership to vet the materials for the education and training program that they planned to use in continued trainings as the program

was being scaled up. In this effort they also paid for the local *promotoras* time to complete the review of materials.

Additionally, directly addressing needs, such as lack of access to healthcare, can also prove to be valuable in uninsured Hispanic populations. This proved to be helpful in a study that increased the number of health screenings among Puerto Rican community by using medical students and medical schools within the partnership (Garcia-Rivera, 2017). Providing a direct service or resource is a way to provide direct care and improve communication and individual health empowerment.

### *Limitations*

A common limitation in CAPs that involve detailed community engagement is a lack of financial resources. Financial resources can influence the degree of involvement and collaboration of community partnerships and throughout the spectrum of community engagement. Additionally, funding is important to be able to provide incentives that will serve as a countermeasure for showing respect for participants' time and presence when working with communities that are limited in time to participate in research.

A practice that was adopted at the University of California, Davis Perinatal Origins of Disparities (POD) Center is leveraging University funding opportunities to fund activities in the community partnership with Resilient Yolo (RY). If there is knowledge of funding as a limitation to any early engagement or ongoing evaluation, it would be prudent to include community members as part of the grant application writing process. This is a mutually beneficial practice that can leave the community with a skill and offers community empowerment in grant writing and financial literacy. In the POD Center and RY partnership, RY participated in the grant development process to provide context and background. Members of

RY have grant writing experience; however, it was a good partnership building activity to get to know more about community partner work. This would likely be beneficial for any partner not familiar with grant writing.

Identifying facilitators to barriers and inhibitors can potentially address limitations. Figure 2 shows a compilation of common barriers to research participation and partnership engagement from Hispanic communities. These were compiled referencing the four studies in Table 1.

**Figure 2.**

*Barriers to Consider*

<p><b>BARRIERS TO CONSIDER</b></p> <p>The following barriers to research and partnership engagement from Hispanic communities span across various levels within the socio-ecologic model. The various activities within Community Academic Partnerships can facilitate participation and have shared outcomes to build and maintain trust. There are also inhibitors to participation that must be considered.</p>		
INHIBITORS	BARRIERS	FACILITATORS
Lack of bilingual members or diverse representation	Linguistic Barriers - Monolingual	Bilingual team members in academic and community level
Focusing on researcher/academic goals	No Perceived Direct Benefits	Community-Informed Research/User Design
Lack of community knowledge/context	Difficulty to Participate	Increased Education and Knowledge Sharing
Short or infrequent engagement	History of Researcher Abuse/Lack of Respect	Incentives and Community-oriented activities
		Continuity/Sustainability Plan

## **Implications**

### **Implications for Hispanic and Population Health Outcomes**

The implementation of practices that are informed by CBPR principles can strengthen the ability for academic partners to establish and build trust in Hispanic communities in community-academic partnerships. Trust-building principles also have an impact on future research outcomes and effectiveness in interventions that can address health disparities and make progress towards health equity for Hispanic communities, and other underrepresented minorities. The results from CAPs that are community-based and community-informed can increase and deepen the understanding of how interventions can positively or negatively impact health in Hispanic communities and other under-represented communities.

The data on health outcomes shows Hispanic populations have been disproportionately impacted by chronic conditions and diseases regardless of existing modalities and treatments. This can be attributed to complex sociocultural and socioeconomic factors, and barriers. Studies that are community-based have shown it is possible to increase treatment adherence in Hispanic populations for diseases such as diabetes, hypertension, stroke prevention, and chronic kidney disease, if the treatments provide the support that addresses barriers (Goldfinger, 2012; Mabachi, 2012)

### ***Individual and Interpersonal Implications***

The implications for building and establishing trust from CBPR principles are significant for individual health behaviors and can inform population health approaches. Community engagement that provides opportunities for input at various phases and levels allow individuals to identify solutions that are empowering to them in future research.

With early engagement in research design, individuals can see the direct benefit in them knowing there will be a return on investment from early participation. As noted by Cunningham-Erves (2020), individuals who were given additional information on the consent process expressed a greater likelihood of participating in the study. Individuals gain knowledge of the research process and can see the benefits in future participation. This can also serve as an opportunity to provide education on informed consent. Individuals can take the information gained from research participation and integrate it into their families and communities. This can increase intergenerational interest in research and increase the possibility for more youth to be interested in research. Individuals participating in research can be advocates within their communities for treatments or interventions (Cunningham-Erves, 2020).

Increased research in Hispanic communities can also serve as a form of outreach and health education. This has been modeled in train the trainer models in which individuals are empowered to educate others (Askari, 2017). This has also been done in trainings where individuals with diseases or conditions are empowered to become peer leaders and take on roles of educating others or even conducting some of the researcher roles in communities (Spencer, 2018).

### *Implications for Partnerships*

Increased participation in study design builds trust and can increase future participation in research studies and other community outreach activities, more so than just having been part of study as a participant (Scharff, 2010; Israel, 1998, 2005). Although lengthy, CBPR informed research gives academics an opportunity to engage with the community and become a trusted partner (Israel, 2005). These partnerships can be leveraged during important times when public and private institutions need to partner with communities to mobilize change. These relationships

can prove to be important in response to disease outbreaks, such as COVID-19, where public health institutions need flexible partners to ramp up contact tracing services or start up community-based research on the short-term and long-term impacts to specific population groups (Michener, 2020).

Academic institutions can strengthen their relationships with the communities in which they reside and add to evidence-based implementation science (Aisenberg, 2012). This also offers an opportunity for students to learn about community engagement and the importance of establishing a sense of community that is not limited to their culture or generation. Communities can provide non-traditional perspectives and approaches to academic researchers. Academic institutions provide a way in which there can be an increase in evidence-based science. There is an opportunity to increase social networking and connections between community members, academics, and even larger public and private organizations. Some CAPs are focused on creating Community Advisory Boards (CABs) that bring together community members with private or governmental partners and subsequently inform local policies or create shared opportunities (Israel, 2005). These partnerships can also provide an opportunity for increased funding to communities due to demonstrated ability for building and maintaining strong partnerships.

### *Implications for Public Health*

The results from CAPs also reaffirm evidence firsthand on systemic barriers to treatment and interventions that can inform future social and healthcare investments. CAPs provide an opportunity for researchers to connect with the community and hear firsthand how their success in receiving treatment or improving their health is impaired. The increased documentation provides evidence across the socio-ecological model that can inform public health and health care policies around access, adherence, and utilization. Various literature on CAPs mentions lack

of access to healthcare, poor built environment, lack of civic engagement, and lack of funding as challenges that impact health (Mabachi, 2012; Villegas, 2020). These partnerships have the potential to increase the ability for community level interventions that occur in these health and social systems to become evidence based and inform broader public health policies and programs.

### **Considerations**

The implementation of these practices will require time, commitment, and willpower. Various CBPR partnerships identify time as the biggest challenge (Cunningham-Erves, 2020; Drahota, 2016); Spears Johnson, 2016). Community based or community informed research needs to be both well thought out and flexible to allow for multiple collaborations without straining quality of engagement.

Additionally, since the partnerships and research take time, the results may not be easily visible or sometimes they become misaligned with academic research leadership priorities. Academics must make a commitment to the communities they engage and must think creatively about how to stay engaged with communities when there is no active work or collaboration. Therefore, ongoing analysis of community strengths, structure, and dynamics are important to ensure academic partners are getting to know the community, and the research or intervention is relevant to the community needs.

Trust building requires a dedicated team and many times the roles and abilities on the academic and community side change. Academic and community members must be ready to adjust and incorporate any new individuals to the partnership. Academics must make staff turn-around a priority in research design and find ways to reduce the number of transitions and or

make them as seamless as possible. Due to the lack of racial and ethnic representation in research, it is also difficult to find culturally and linguistically competent researchers (Christopher, 2008). This can be a significant problem in a Hispanic partnership if key team members who communicate with the community leave and there is difficulty backfilling a role that addresses linguistic or cultural barriers. A way to mitigate this in academic settings is to recruit and mentor culturally competent undergraduate or early career researchers who are pursuing a post-graduate education or a career in academia and can develop continuity in their work with a specific community. Additionally, ensuring during interview process that there are questions on how the interested researchers long-term goals contribute or align with the those of the community.

### **Conclusion**

The implementation of trust building and maintenance by applying practices informed by CBPR principles can increase the effectiveness of community engaged research in Hispanic communities. In the long-term, this can also improve the health outcomes of the Hispanic community with more research that is community-informed to the needs of the Hispanic community. The practices will require commitment from both academic and community partners to ensure trust enabling practices such as ongoing knowledge transfer of the agreed upon community role and definition, as well as ongoing education on the subject matter of interest and the research process. Additionally, the dedication to including community members as part of the research design process so that the study can be community-informed and not just community-based results. And lastly, and we think of building trust, there should be an accountability measure such as the progress on the continuum of community engagement.

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**Appendix****Appendix A – Glossary of Abbreviations**

<b>Abbreviation</b>	<b>Term</b>
CAP	Community-Academic Partnership
CAB	Community Advisory Board
CBO	Community Based Organization
CBPR	Community Based Participatory Research
EBI	Evidence-Based Intervention
EBP	Evidence-Based Practice

**Appendix B - MPH Foundational Competencies**

MPH Foundational Competencies

Foundational Competency	Description of how used for Capstone
<b>Evidence-based Approaches to Public Health</b>	
1. Apply epidemiological methods to the breadth of settings and situations in public health practice	
2. Select quantitative and qualitative data collection methods appropriate for a given public health context	
3. Analyze quantitative and qualitative data using biostatistics, informatics, computer-based programming and software as appropriate	
4. Interpret results of data analysis for public health research, policy and practice	
<b>Public Health &amp; Health Care Systems</b>	
5. Compare the organization, structure and function of health care, public health and regulatory systems across national and international settings	
6. Discuss the means by which structural bias, social inequities and racism undermine health and create challenges to achieving health equity at organizational, community and societal levels	
<b>Planning &amp; Management to Promote Health</b>	
7. Assess population needs, assets and capacities that affect communities' health	
8. Apply awareness of cultural values and practices to the design or implementation of public health policies or programs	Identified sociocultural values in Hispanic community with a highlight on trust and the potential impact and considerations to mitigate trust for research participation and individual health behaviors.
9. Design a population-based policy, program, project or intervention	
10. Explain basic principles and tools of budget and resource management	
11. Select methods to evaluate public health programs	
<b>Policy in Public Health</b>	
12. Discuss multiple dimensions of the policy-making process, including the roles of ethics and evidence	

<p>13. Propose strategies to identify stakeholders and build coalitions and partnerships for influencing public health outcomes</p>	<p>Identified strategies that influence recruitment and retention of community partners to expand outreach into Hispanic communities and create the foundation for a relationship to involve them in the academic/community partnership.</p>
<p>14. Advocate for political, social and economic policies and programs that will improve health in diverse populations</p>	
<p>15. Evaluate policies for their impact on public health and health equity</p>	
<p><b>Leadership</b></p>	
<p>16. Apply principles of leadership, governance and management, which include creating a vision, empowering others, fostering collaboration and guiding decision making</p>	<p>Identifying community-based participatory research principles, community-based participatory research informed practices, and community engagement continuum as tools for guiding collaboration with the Hispanic community.</p>
<p>17. Apply negotiation and mediation skills to address organizational or community challenges</p>	
<p><b>Communication</b></p>	
<p>18. Select communication strategies for different audiences and sectors</p>	
<p>19. Communicate audience-appropriate public health content, both in writing and through oral presentation</p>	<p>Outlined, drafted and finalized Capstone paper including a literature review, recommendations and implications on a current public health problem. Created a slide deck based on the Capstone paper and delivered an oral presentation at Health Professions Day in front of an interprofessional audience.</p>
<p>20. Describe the importance of cultural competence in communicating public health content</p>	<p>Identify priorities for academic partners seeking to engage the Hispanic community in a culturally competent approach and identify practices to establish trust.</p>
<p><b>Interprofessional Practice*</b></p>	
<p>21. Perform effectively on interprofessional teams</p>	
<p><b>Systems Thinking</b></p>	
<p>22. Apply systems thinking tools to a public health issue</p>	<p>Applied the community engagement continuum against common community</p>

	academic partnership practices and along community based participatory research scale as an evaluation tool.
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Health Policy Leadership Concentration Competencies

Competency	Description of how Capstone used
1. Apply economic concepts to understand the effect of changes in policies at the government, health systems, and public health sectors	
2. Synthesize economic concepts to assess equity and efficiency in making health policy recommendations in underserved communities	
3. Formulate efficient health policy change recommendations through the analysis of proposed health policy initiatives that could affect health outcomes of vulnerable populations	
4. Develop recommendations to improve organizational strategies and capacity to implement health policy	Identify common trust-building practices community academic partnerships should adopt to address health disparities in Hispanic communities and strengthen research outcomes when evaluating treatment or interventions.
5. Analyze policy options to address environmental health needs at the local, state, and federal levels	