

Guidelines for Conducting Health Research **WITH** Latino Border Communities and Promotores de Salud

In collaboration with:

New Mexico Border Health Research Work Group, Community Engagement Core, New Mexico CARES Health Disparities Center, University of New Mexico, and New Mexico State University

Funder: National Institute on Minority Health and Health Disparities, National Institutes of Health, Grant No. P20MD004811-02

TABLE OF CONTENTS

ABOUT THIS PUBLICATION.....	pages 3-4
OVERVIEW.....	pages 5-8
PLÁTICAS.....	pages 9-11
VIGNETTES, DISCUSSION QUESTIONS, and RECOMMENDATIONS.....	pages 12-25
REFERENCES.....	page 26-27
APPENDICES.....	page 28-32

Cover Photo:

The Paso del Norte region is located at the virtual midpoint of the 1,500-mile border shared by the United States and México. The binational metropolitan area is situated 1,700 miles southwest of Washington, DC, and 970 miles northwest of Mexico City. Almost 100 million U.S. residents (33% of the U.S. population) and 91 million Mexican residents (79.3% of México's population) are accessible within a 1,000-mile radius (1,600 km).

Regional Stakeholders Committee. 2009. *The Paso del Norte Region, U.S.-México: Self-Evaluation Report*. OECD Reviews of Higher Education in Regional and City Development, IMHE.
<http://www.oecd.org/edu/imhe/regionaldevelopment>.

ABOUT THIS PUBLICATION

This publication was produced collaboratively with members of the New Mexico Border¹ Health Research Work Group, comprised of Intercultural Health Disparities Scholars affiliated with the NM CARES Health Disparities Center at the University of New Mexico. The purpose of these guidelines is to help build trust and mutual respect between community and academic partners. Positive working relationships that value the role of *promotores de salud* (community health workers) in the partnership are critical for conducting research *with* Latino and border populations.

Border Health Research Work Group (BHRWG)

The Community Engagement Core of the NM CARES Health Disparities Center, along with partners, identified the need to address how *promotores de salud* were involved in research in the border region. As a result of strategic planning, a working group was established in 2012 in order to develop guidelines for conducting research with Latino border communities. The group consisted of eighteen members on the planning committee and an overall group size averaging forty-six members.

Vignettes or scenarios of the partners' experiences in the research process were discussed during intercultural dialogues, trainings, work groups, and teleconference meetings that occurred between January 2012 and March 2014. The following meetings took place:

- January 20, 2012: Intercultural Dialogue for Conducting Research WITH Border Communities and Introduction to Community-Based Participatory Research, Hotel Encanto, Las Cruces, New Mexico
- August 15, 2012: Border Health Research Work Group, Farm and Ranch Museum, Las Cruces, New Mexico
- November 5, 2012: Border Health Research Work Group
- January 25, 2013: Work Group to Develop Guidelines for Conducting Research WITH Latino Border Communities, Pan American Health Organization, El Paso, Texas, and Las Cruces, New Mexico
- April 11–12, 2013: Community-Based Participatory Research Training and Health Equity Policy, Farm and Ranch Museum, Las Cruces, New Mexico
- June 6, 2013: Teleconference call, Work Group
- July 24, 2013: Meeting, Work Group, Doña Ana County, Las Cruces, New Mexico
- August 2013: Teleconference call, Work Group
- November 2013: Teleconference call, Work Group
- February 2 and 27, 2014: Meeting with Silvia Sierra, member of BHRWG, on developing vignettes

¹ As defined in P.L. 103-400 (22 U.S. Code, 290 n-5) and the La Paz Agreement of 1983, the border region is approximately 2,000 miles long and is legally defined as the area 100 kilometers (62 miles) north and south of the U.S.-México border. Migration occurs not just between north and south but also between east and west. Source: http://www.borderhealth.org/border_region.php.

- January–February 2014: Pláticas with community members on developing vignettes
- March–April 2014: Pláticas with cultivating communities (researchers, health practitioners/leaders, and promotores de salud)

Reflections with community members and researchers, in the form of Pláticas in the Paso del Norte region up through the Rio Grande corridor of Albuquerque, New Mexico, culminated in the vignettes that form the core of this document. Clara Silvia Sierra, a bilingual consultant and collaborator from Doña Ana County, New Mexico, who has vast experience working with border communities, collected and drafted the vignettes. Lisa Cacari-Stone, a professor in the Family and Community Medicine Department at University of New Mexico, directed the production of the process and the writing and content of the publication. Nora Chavez assisted in developing the vignettes, designing the publication, facilitating the community outreach process, and organizing logistics. Liana Quinn-Hussein conducted the literature review for best practices. The Community Engagement Core (CEC) Team of the NM CARES Health Disparities Center developed the model for conducting health research *with* communities. From 2009 to 2014, the CEC team members included Lisa Cacari Stone, Nina Wallerstein, Clarence Hogue, Norah Chavez, Lucinda Cowboy, Alison McGough McDuenas, Angelica Solares and Nina Wallerstein. Consultant Roberto Chene was instrumental in developing a “with” approach to doing research and creating the focus on “intercultural” relationship building.

More than thirty reviewers provided comments and feedback to strengthen the document. We wish to acknowledge the following reviewers: Anabel Canchola, Dr. Hugo Vilchis, Carmen Maynes, K’Dawn Jackson, Sylvia Sapien, Susana Martinez de Gonzales, Ernesto Stolpe, Beatriz Favela, Dr. Gina Nuñez, Cruz Saenz, Norma Saenz, Veronica Perez, Magdalena Loya, Marta Hernandez, Teresa Herrera, Isabel Muñoz, Graciela Calamaco, Lourdes Hernandez, Lorenza Hernandez, Imelda Garcia, Yvonne Gomez, Elva Quimby, Donna Sandoval, Holli King, Marsha Rippetoe, Lorraine Navarette, Susan Kunz, and Marnie Nixon.

Some members of the ad-hoc group presented the vignettes at the 2014 New Mexico Public Health Association and NM CARES Health Disparities Center Joint Conference on Health Disparities in Albuquerque in April 2014. Participants voted on the best questions for discussion and recommendations. The top choices and best practices are included after each vignette, as well as best practices of community-engaged research from the literature.

We gratefully acknowledge the support of the National Institute on Minority Health and Health Disparities, grant number P20MDOO4811-02. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institute on Minority Health and Health Disparities or the National Institutes of Health.

Suggested citation:

Cacari Stone L., Sierra S., Canchola, A., Quimby, E., Saenz, C., Hernandez, M., Chavez N., Quinn-Hussein L. and Bettez, S.P. *Guidelines for Conducting Health Research with Latino Border Communities and Promotores de Salud*. Albuquerque, NM: NM CARES Health Disparities Center, Community Engagement Core, University of New Mexico; 2015.

OVERVIEW

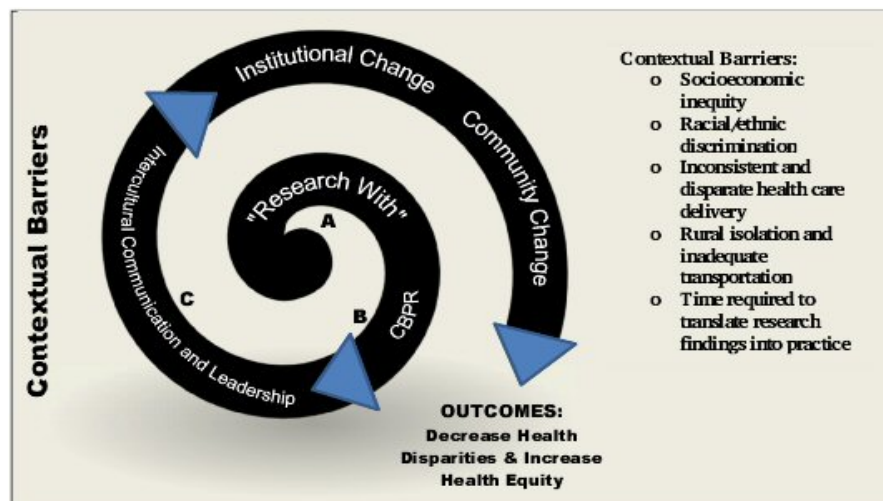
Motivation and Approach

Health inequities are a national, state, and U.S.-México border problem. Research can improve health and eliminate inequities by informing and testing solutions that work. Community participation in research is key in contributing to the health of future generations. Yet many challenges exist to effective partnerships—for example, a legacy of mistrust and ethical abuse of people of color in research studies or the lengthy timelines it takes to build partnerships. Recognizing these challenges, the National Center of Minority Health Disparities (NIMH) increased funding to academic institutions so they could create Health Disparities Centers to strengthen relationships between the institutions and racial/ethnic communities.

Engagement initiatives reflect a continuum, from communities being subjects or recipients of the research findings to communities being equal partners in codeveloping and implementing the research methodology and translating and disseminating the findings together (Cacari-Stone et al., in progress).

There is a need to develop community-driven principles and practices that benefit not just individuals but specifically the growing demographic, “Latinos/Hispanics” and Latino communities living in the Southwest border region. To address this gap, the NM CARES Health Disparities Center Community Engagement Core (CEC) worked with key border health partners to develop this publication, which can be used as a tool for convening *pláticas*. The *plática*, which is translated as “conversation” or “informal talk,” is a cultural and linguistic tradition used by Latino communities to engage in meaningful and authentic exchanges around critical issues affecting our children, families, and communities. The following framework was developed as a guide for conducting research *with* communities and is rooted in principles of community-based participatory research (CBPR) and decolonized and feminist research approaches. Changing from an approach to conducting research ON or IN communities to a *with* approach is grounded in the premise that universities and other organizations conducting research must also look ‘within’ to develop policies and practices that shift from a culture of research as an independent enterprise to one of engagement.”

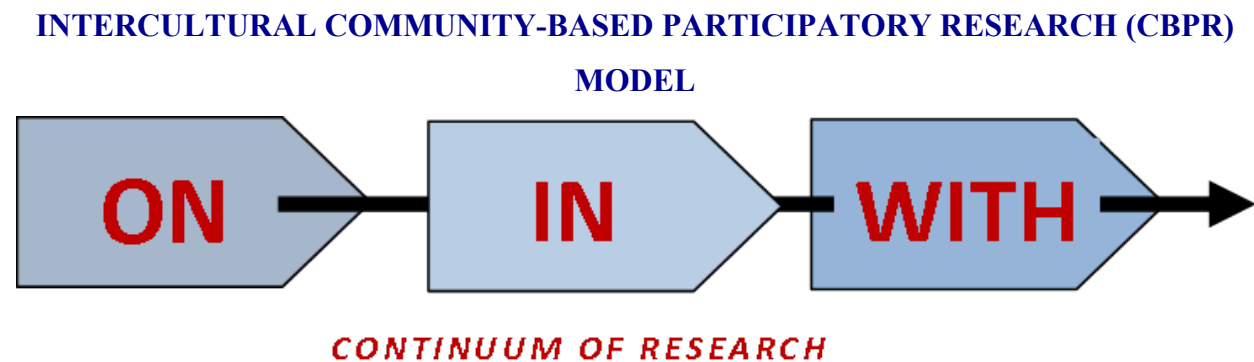
Figure 1



Guiding Framework for Conducting Health Disparities Research

The guiding framework and model below describe how the community and institutional changes can happen while overcoming barriers (discrimination, socioeconomic inequity) when the research relationship and processes are built upon principles of *Intercultural Partnership and Community-Based Participatory Research (CBPR)*. The NM CARES HD through the Community Engagement Core will identify and recruit academic and community partners to become Intercultural Health Disparity Scholars, using this framework as a guide.

Figure 2



A. Research with Communities

In order to move towards institutional and community change, dialogues between academic and community members are needed. The focus of the ongoing dialogues should be on *how* we shift our thinking about doing community research from using an “on/in” approach to a “with” modality. The figure above illustrates a continuum of research that occurs between universities and communities from “doing research on” to “doing research in,” with final movement towards “doing research with.”

B. Community-Based Participatory Research (CBPR)

CBPR is described as supporting “collaborative, equitable partnerships in all phases of the research.” This is achieved through a *colearning and capacity building* process among all partners. All research findings and knowledge gained are shared with all partners. CBPR involves a *long-term process* and commitment from both researchers and community (Israel et al. 2003, 56-58).

C. Intercultural Communication and Leadership

- Include cultural diversity at the center of how things are conceptualized and implemented across research projects.

- Expand the definition of community and research partners to Intercultural Allies who mutually advocate for one another to guarantee community voice and perspective in the outcomes relating to the elimination of health disparities.
- Intercultural Allies are trusted individuals.
- Be aware of and help equalize power differentials between community experts and the research institution.

Purpose

The *Guidelines for Conducting Health Research WITH Latino Border Communities and Promotores de Salud* outline key considerations taken in addressing issues and developments of communication and interaction within the realms of language, tradition, culture, and historical trauma as applicable to this population (Estrada 2009) and institutional racism. Promotores de salud and other community partners engaging in research with universities will want to use this document to provide protections and support that will allow them to confidently root their practices in the knowledge, values, and needs of the communities in which they live.

Audience

The primary audiences for this document are promotores de salud, researchers working with Latino border communities, academic institutions, and research organizations and agencies. It is also intended for anyone who has a stake in conducting research in his or her community, including health practitioners and administrators, academic and nonacademic researchers, students, and policy makers.

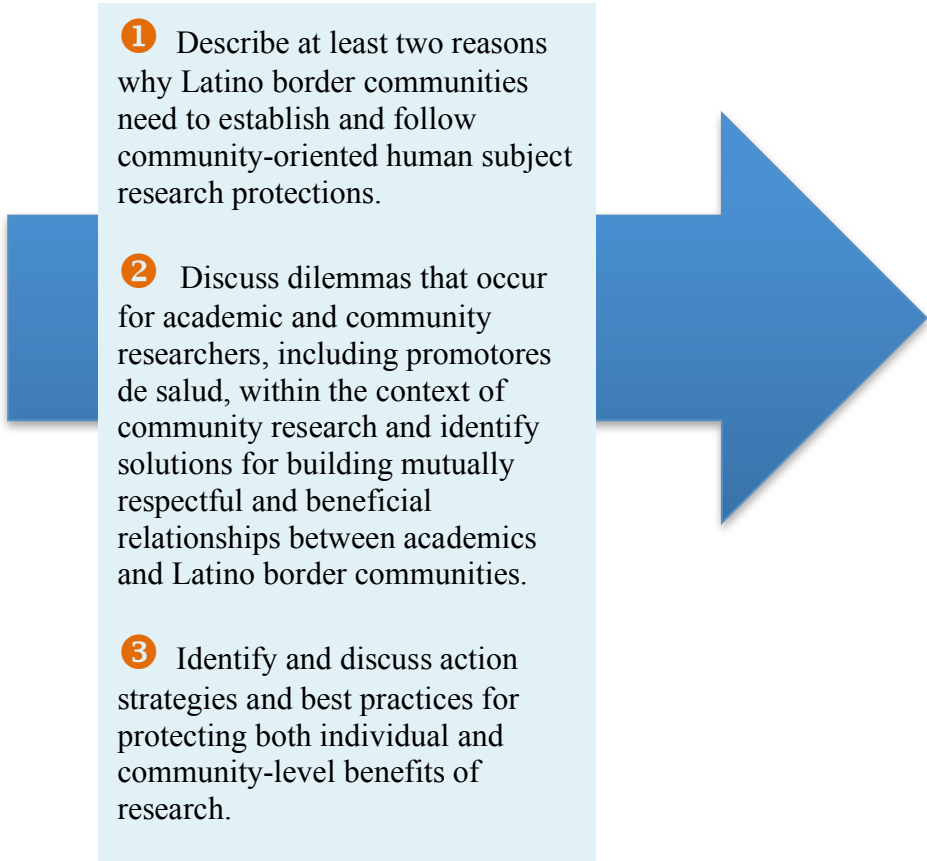
Dialogue and Training

This publication intends to promote further dialogue and to serve as a useful and practical tool for training community members, health leaders, practitioners, researchers, and students. The authors recommend using the publication in pláticas with small groups. The use of the tool within the plática aims to engage partners in identifying best practices and interventions that will guide them in conducting research WITH Latino border communities. Pláticas should last between three and four hours, and the topics should include the review and discussion of the principles, vignettes, and actions that draw from best practices to promote mutually beneficial relationships. We hope to build a strong network of pláticas in the region that will move principles to action and over time improve the nature of the research and expand the application of knowledge to advance health and social change.

The vignettes outline key considerations in addressing issues and developments of communication and interaction within the realms of language, tradition, culture, and historical trauma when working with Latino border communities in New Mexico and the Paso del Norte area. Each vignette introduces a principle, followed by a dilemma or circumstance that illustrates the application of that principle. The principle or value illustrated by each vignette is one that the participants identified as essential for their work with researchers. Each vignette includes questions for discussion, followed by recommendations and best practices, as well as relevant findings from the literature.

Learning Objectives

By the end of each plática, participants should be able to:



1 Describe at least two reasons why Latino border communities need to establish and follow community-oriented human subject research protections.

2 Discuss dilemmas that occur for academic and community researchers, including promotores de salud, within the context of community research and identify solutions for building mutually respectful and beneficial relationships between academics and Latino border communities.

3 Identify and discuss action strategies and best practices for protecting both individual and community-level benefits of research.

PLÁTICAS

Pláticas are a Hispanic/Latino/a tradition of conversation that encourages relationship building around mutuality and reciprocity. This allows for a free exchange of information and ideas among individuals in groups. The tradition facilitates understanding of one another's cultures and commonalities when working toward community engagement. We recommend using this method of communication to discuss the vignettes with academic and community partners, including promotores, who are conducting or considering doing research with Latino border communities.

Preparation

About two weeks in advance, send an invitation to the participants. Explain the meaning of upcoming plática and specify:

- Why (the reason for the gathering)
- What it will be about (contents and title)
- Where it will take place (location and directions)
- When (date, time, and length)

Plan on at least three hours, preferably four.

Prior to the plática, prepare these materials:

- Name badges
- Folders with agendas and handouts
- Flipchart with the agenda, the frame wording, and the objectives
- Markers
- Masking tape

Make sure you are familiar with the space for the meeting and that the location is considered accessible and welcoming to the community. Although you may want to send an agenda in advance, each plática will move at its own pace and rhythm, and each gathering will be unique in format and content. Make food and refreshments available, childcare if needed, and if possible offer community members and promotores travel support and stipends to compensate them for their time if their employers do not sponsor them.

Structure

Welcome (fifteen minutes): When participants arrive, greet everyone and quickly introduce new people if necessary. Allow about fifteen minutes for informal greetings among participants if they know each other.

Housekeeping (five minutes): Provide important information about facilities and training logistics.

Introductions (up to an hour): Over lunch around a large round table, everyone begins to settle into informal conversations about families, work, and happenings in their communities. Depending on the group’s location, the participants speak in English, Spanish, or a combination of the two. Start the plática with a question or story to give everyone the opportunity to relate his or her experiences. For instance, you may want to ask: “What motivated you to become promotores and how do you feel in your role as helper in your community?” Or inquire, “What have you experienced as part of a research team with a university?” Or “What does today’s topic mean to you?” If it is a mixed group of academic and community partners, you may ask the academics: “What caused you to become a researcher and how do you feel in your role as a researcher working with community helpers?” Or post the question “What is your experience in working with promotores?” Aim for allowing each participant to tell his or her story without interruptions.

Familiarity with Participatory Research

Next, assess the familiarity of the group with participatory research, using a flip chart to document the various exposures and experiences. Ask the participants to offer some stories or examples of research projects they have worked on and the positive experiences and/or challenges they had. Record responses on a flip chart. This is a critical step in ensuring that each person in the group is validated and her or his experiences are equally valued. The facilitator then summarizes the collective experiences that have been shared and highlights a few common themes.

Discussion

The next step is to have a general discussion about research itself, highlighting a process that fosters mutual respect and engagement, is participatory, and is rooted in the principles of community-based participatory research that are described above in figure 2.

Principles to Follow When Conducting Research WITH Latino Border Communities

The *flor de tilo*² in figure 3 below serves as a useful symbol to show the parts of the process we recommend in these guidelines. (The graphic was developed with promotores as part of the research process.) The stem of the flower represents the Latino border communities; the two leaves represent the United States and Mexico; and the six petals are named after each of the six principles that emerged from the vignettes. The perimeter of the flower has eight arrows pointing clockwise in a circle. Each arrow shows a stage of the process we followed in a collaborative and inclusive research project:

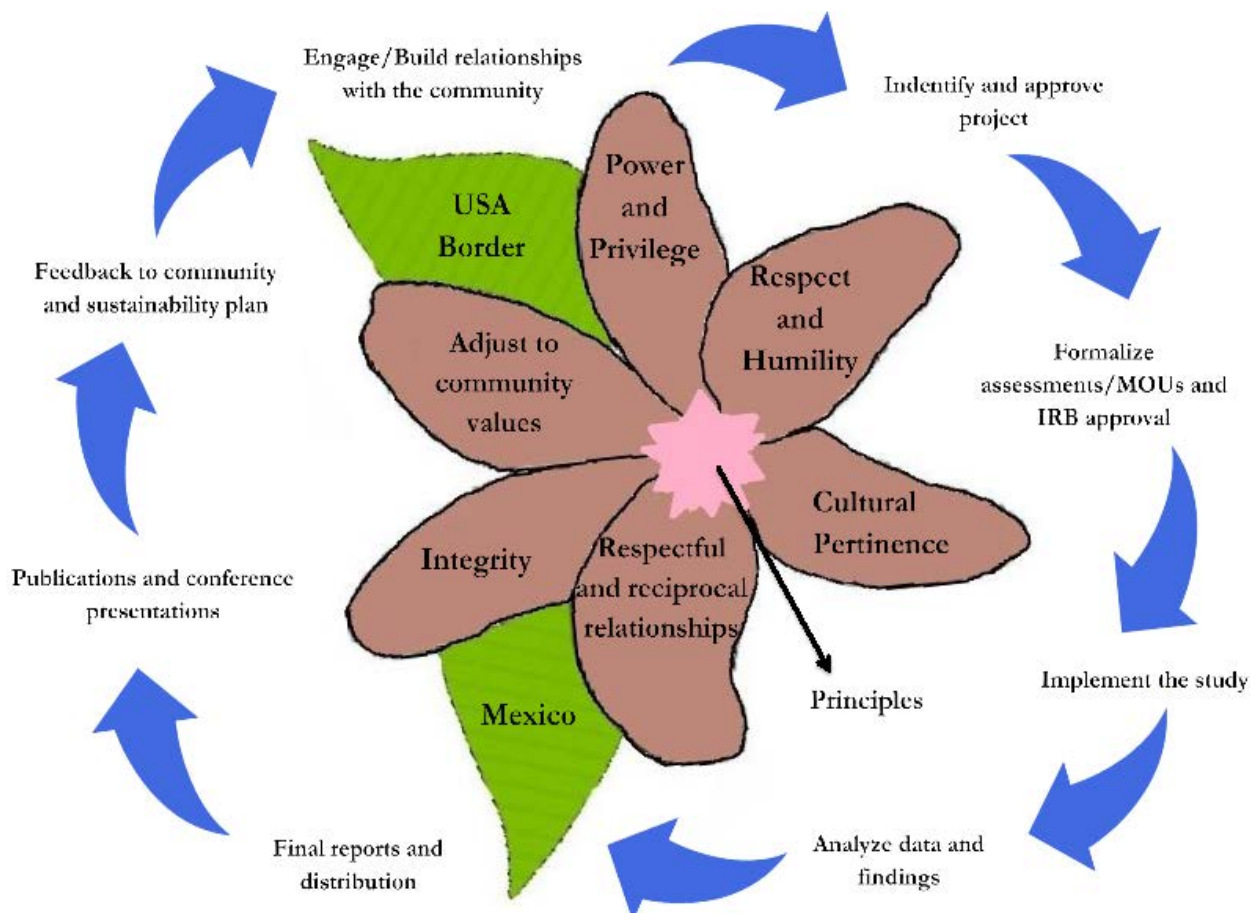
1. Develop ties and relationships.

² *Flor* means “flower,” and *tilo* means “linden tree.” People in many countries use an infusion of flor de tilo to alleviate colds, ease headaches, and prevent anxiety by calming the nervous system.

2. Identify and agree on the project.
3. Formalize agreements and apply for internal review board approval.
4. Implement study.
5. Analyze data and findings.
6. Write and disseminate reports.
7. Publish manuscripts; plan presentations at conferences.
8. Reconnect with the community to assess benefits of the research and plan for sustainability.

Figure 3

Guide to Principles for Conducting Investigations in Latino Border Communities



VIGNETTES

Vignette 1

Principle: Cultural Relevance Along the U.S.-Mexico Border

Culture is an important part of people's lives. It impacts their views, values, and hopes and reflects their worries and fears. People from diverse cultures live in New Mexico, and it is important to learn about the culture of each place and its people. Traveling across the state, we find indigenous people from Native American reservations, from pueblos, and from urban areas. Latinos or Hispanics from New Mexico are diverse and may originate from the United States, Spain, Mexico, Guatemala, Ecuador, or other Central and South American countries, and they be documented or undocumented.

By establishing relationships with people from cultures different than our own, we learn to create robust and lifelong alliances. In order to build strong(er) communities that can be successful in initiating change within and outside of their boundaries, we—individual researchers and university institutions—need to understand and appreciate the variations in cultures and ways of life. Border communities have a culture of their own. To work effectively in the border with Mexico when conducting research, it is advisable to know Spanish, appreciate the food, and understand cultural differences, such as norms about time and the meaning of respect.

For instance, pláticas with promotores more often than not happen around food. Sharing food is traditionally the way Latinos open up and create a safe space to exchange conversation and establish rapport and *confianza* with others. Sharing a meal for the most part is expected, and not partaking in the gesture may make the hosts feel shunned or cast off. The concept of time is not often based on a clock, and meetings may have a slow start because participants take time to greet and acknowledge one another. Being respectful and present is more important than being on time.

In the course of a plática, participants will greet one another, and it is common for them to hug (*abrazar*) everyone—including the researcher—and to be physically close to other community members. Pláticas with promotores and with most members of border communities are conversations that take place within a context of other social relationships (*la tía, la prima, la comadre, y la amiga*). Everyone must know someone so that, when they get together, those in attendance are not strangers.

Promotores work/collaborate with researchers in binational projects. The promotores rarely hesitate to assist investigators, partly because they assume that their communities will benefit from their participation in the research. Promotores and communities along the border have been active, knowledgeable, and skilled contributors in research. They have been valuable partners in

studies, understand the search for solutions through research, and see the potential to improve the living conditions of Latinos and border residents, especially in colonias.³

The former was displayed during a monolingual plática in Spanish with promotores and community residents in southern Doña Ana County. After greeting one another with hugs and sharing family updates, all the guests sat around the kitchen table and delighted in Oaxacan mole, beans, and tortillas, as one of the promotores shared the experience of working in the border with a binational federally funded project. The facilitator began the discussion with the group on the importance of “cultural relevancy.” She asked the group for their comments and insights.

The independent promotora had been contracted by higher education institutions for various research projects and was proud of her accomplishments. This promotora was well versed on the institutional review board (IRB)⁴ process and the value of such a process to lay out rules, guide their work, and set boundaries as they collaborated with researchers and promotores in Mexico. As promotores became active participants in this binational wastewater project with their Mexican counterparts, they observed that promotores in Mexico were not aware of the IRB process required by universities for research with human subjects. (See Appendix 1.)

A member of the promotora team stated, “In México, the promotores are hard workers, they work anywhere, anytime, even helping dig the ditch for the wastewater! And us in the U.S, we have many rules that limit the work we can do, we are protected.”

The discussion was of concern for promotores on the Mexican side, because even though they had more freedom to conduct their work, promotores in the United States felt that Mexican peers had been taken advantage in terms of their time, and they had not been protected by the association with the researcher or institution they represented. Yet promotores in the United States knew that thanks to the IRB process and to the well-trained principal investigator, they were not faced with such a dilemma. Based on the discussion of one promotor, the principal investigator of this university was strict in her expectations of her team adhering to the IRB process, and the stance was appreciated.

Those who participated in the pláticas felt that the principal investigator set the tone and modeled just, fair, and ethical rules for all involved, including the students, promotores, staff, and, most

³ The United States Office of the Secretary of State defines a colonia as a residential area along the Texas-México border, usually located in an unincorporated area of a county, with all parts of that county at least 150 miles from the border. Colonias may lack some of the most basic living necessities, such as potable water and sewer systems, electricity, paved roads, and safe and sanitary housing. Most families living in colonias have very low income, as defined by the local government. For more information see <http://Legal-Issues-in-NM-Colonias>.

⁴ An institutional review board (IRB) is a committee established to review and approve research involving human subjects. The purpose of the IRB is to ensure that all human subject research be conducted in accordance with federal, institutional, and ethical guidelines. See <http://www.apus.edu/community-scholars/institutional-review-board/>.

significantly, the community. Understanding the importance of protecting all human subjects on either side of the border, of knowing the protocols, and of informing and training both promotores and communities is critical for all participants in research along the border, including the principal investigator.

Questions for Discussion

1. What should researchers know about the Latino border culture in order to gain trust and be considered respectful of cultural differences?

Recommendations and Best Practices

1. Involve the community from the beginning to help researchers and promotores build mutual trust and respect.
2. Understand that promotores expect a benefit to their communities from the research.
3. Consider cultural adaptation to the IRB process. Create a process or dialogue with the Mexican promotores ahead of time so that they are aware of the IRB process.
4. Engage with Mexican institutions regarding IRB requirements; use the Institutional Review Boards in the U.S.-Mexico Border (2010) as a guide for developing and adhering to human subject ethics and protections.
5. Meet binationally and cross-share information, discuss ethical issues regarding human subjects in research and process.

Comments from the Literature

Promotores are community experts. They are caring, credible, and trusted by the community. They are concerned about the well-being of others and capable of creating egalitarian relationships in order to help others—and themselves. This process of relationship building has the capacity to transform the community. (Latino Health Access et al. 2011, 6)

Challenges Around the IRB Process

IRBs are unfamiliar with CBPR (Resnick, Kennedy 2010), and communities are often unaware of the role of IRBs (Hyatt et al. 2009). This lack of knowledge leads to problems such as reluctance to engage in ongoing research-partner interaction and refusal to allow researchers to report back to the community. Researchers who work with communities acknowledge that communities also are not aware of the CBPR process (Hyatt et al. 2009) and that IRB practices do not always meet the needs of promotores and their communities. Both the promotores and the institutions that employ the researchers need to increase their mutual understanding. Considering the ‘legacy of mistrust’ of health research by ethnic and racial communities, we believe it is up to researchers to consider the impact of their research on social conditions that represent social injustice and address these issues with communities (Cacari-Stone and Avila 2012).

Vignette 2

Principle: Respect and Humility

Promotores de salud along the U.S.-México border have opportunities to work with universities in multiple states, as well as to work in México. Most promotores welcome the interaction with bilingual university researchers and/or graduate students who are culturally responsive and eager to learn, who respect the wisdom in communities, and who value the role promotores play each day in their communities.

For community members it is common to participate in the IRB process, engage in community meetings, collaborate in developing the research tools and the evaluation, and work with researchers in coordinating feedback presentations on the results of the investigations. Below is an example of a binational research project that exemplifies the importance of including the promotores in every aspect of the research and of their developing a relationship with the researchers that is based on mutual trust and respect.

In a recent binational wastewater project, funding was available to hire one principal investigator (PI), students, and two promotores from two different communities to work in two counties, as well as some promotores from México. The promotores engaged in training regarding the importance of the IRB as well as methods and practices for outreach in identified target areas. The PI held regular bilingual meetings with the promotores to review the results prior to the community presentations. The following happened.

The promotores were aware that they were expected to present the results of the research to all agencies that assisted with this project, such as school districts and the local Department of Health. They were not asked to review or participate in drafting the final report, but a copy of the report was provided to them to assist in their preparation for the upcoming community presentations.

When the U.S. promotores reviewed the data analysis done by university students, they realized that the data was wrong. There was a discrepancy between the results of the study and the reality of the situation. The promotores were concerned because they didn't want to present inaccurate data to members of their own communities, who would know the report was wrong. Because promotores felt that with this binational project there was a common understanding of one another's roles and respect for all partners, they felt confident of their skills and knew that they were valuable members of the research team. Therefore they were able to tell the research team that the results were wrong. The academic team humbly admitted to their mistake, realized that it could have affected the integrity of the promotores if the data was wrong, and fixed the error before presenting the results to the community.

With great pride and self-confidence the promotores stated, "Because we had a respectful working relationship with the research team, we were able to clarify this mistake!"

Questions for Discussion

1. What would have happened if the promotores had not been listened to or had not come forward?
2. What impact does a promotor have on border research?
3. What is the true value of a voice?
4. How would the institution be discredited by presenting/publishing wrong data?
5. What components or makeup of the team made it successful?

Recommendations and Best Practices

1. Meet regularly and bilingually.
2. Researchers need to acknowledge that promotores often have better knowledge of their communities than they do.
3. Use promotores from the regions in which they live. They are knowledgeable.
4. Engender mutual respect and get to know everyone,
5. Ensure that promotores are involved from the beginning, and in every step of the research process, to demonstrate their importance to the project at hand.
6. Pay promotores per hour, not per packet, when they conduct surveys.

Comments from the Literature

We are a bridge to services, but we have a role to play in making sure that the right services get [to] our community. (Latino Health Access et al. 2011, 15)

The vignette above emphasizes how the knowledge of the communities that promotores have is invaluable to researchers and how a solid relationship between the researchers and the promotores can make all the difference in producing accurate information about community conditions. An article by Johnson et al. (2013) attests to the importance of cultural awareness and relationship building between researchers and promotores. St. John et al. (2013) describe a good example of how promotoras-researchers provide valuable contributions beyond outreach because of their knowledge, skills, and investment in their communities.

Hilfinger Messias et al. (2013) identified benefits and challenges of engaging promotores in community research by using a multisite randomized controlled trial of an intervention for Mexican-origin women in Texas and South Carolina. They identified the strengths and skills of promotores that contribute to enhancing their engagement in research and the valuable contributions they bring to research with communities.

Vignette 3

Principle: Understanding Community Time and Values

Promotores are advocates in their communities and are passionate about the roles they play and the responsibilities they hold for their communities. Often, however, their values and community norms present challenges when promotores work with researchers bound by their own academic cultures and values. Here is an example.

Promotores were troubled by how they were perceived by researchers and administrators and decision makers from foundations or nonprofits when their assistance was requested to work on research projects. Their dilemma was about how researchers perceived promotores. Their concerns were not only felt or seen in southern New México but also in other border states.

At a recent plática promotores voiced their concern about working with the time constraint given on a data-gathering project. Several shared experiences in which they had been asked to conduct surveys as a “check the box” and get in and out of each survey home in no more than fifteen minutes, quickly moving on to the next home. As one of the lead promotores stated, “It is very difficult to just use people [filling out a survey] without giving them a little bit of information, even if it’s just a telephone number.” It is culturally offensive to rush through and interview or survey families without taking the customary time to share a cup of coffee and chat.

Another concern arose because it was common for the families to disclose a great deal about their family challenges as the surveys were conducted. Given their passion and *corazón* (heartfelt commitment) for their clients and communities, the promotores could not possibly just walk away and leave the families in a vulnerable state in order to meet the demands of a time-limited survey. For most promotores, the amount of time spent with each family is not reflected in what they get paid by the researchers. They were also concerned that their characters would be questioned or that they would not be able to deliver ethical services if they followed the time-limited guidelines established by the researchers.

As one of the promotores stated, “The families have needs, and the time to address these needs is when we visit, when we see them, or when they call, NOT when we get a new grant!”

Questions for Discussion

1. As a PI on this project, what would you do differently to address the concerns of the promotores?
2. When promotoras expressed their concerns over culture and time, why are the researchers not taking into consideration the time frames of the community?
3. What is the benefit of using promotores to conduct surveys? They are not “check the box” people.

4. How can researchers use this information to develop research tools?
5. How do you think promotores feel about working with a “check the box” orientation?
6. How can we integrate important values (like helping survey members and not rushing) while working within the limitations of researchers’ grant funding?
7. As PI how would you incorporate the experience of promotores in developing questionnaires?

Recommendations and Best Practices

1. Researchers should take into consideration and respect differences in values and norms when they develop the research tools.
2. When the protocol is being developed, promotores want it to be a questionnaire, not a “check the box” format. The questions should elicit more information.
3. When developing the research protocol, both researchers and promotores should sit down and have a discussion to cocreate the research tools.
4. Promote pláticas for promotores to describe and reflect upon their experiences.

Recommendations from the Literature

Yes, it is important to have the right information to share with people. But it is more important to have their trust so that people will believe in you and trust what you say. (Latino Health Access et al. 2011, 13)

A paper by Michener et al. (2012) focuses on the need to align processes and goals between communities and community-engaged researchers, which implies institutional culture change, in order to effectively address health disparities. This process requires that researchers engage communities with respect in order to establish mutual trust, developing and maintaining relationships over time and changing/challenging the culture of academia to develop new methodologies that will help communities improve their health.

Vignette 4

Principle: Power and Privilege

In a border community outside of El Paso, Texas, two promotores worked with researchers from a nearby university. The researchers had received a grant from a federal agency to assess the incidents of dementia, Alzheimer's disease, and depression along the U.S.-México border. The researchers had preconceived ideas that dementia and Alzheimer's were more prevalent than depression among people living in unincorporated communities.

Promotores were hired after the grant was funded to perform outreach and assess the prevalence of dementia, Alzheimer's disease, and depression. The university researchers wanted to do an assessment of the whole community. As one promotora stated, "They wanted numbers, and they were clear; the researcher wanted to prove to the funding entity what our culture [Mexican] did with our *enfermitos* [people suffering from dementia, Alzheimer's, and depression]. We knew that because the researcher stated that he wanted numbers based on the following priority: dementia, Alzheimer's, and depression.

The number was not expressed, but the priority for showing higher numbers for dementia was. We never saw the results of the report, the researcher and we (the promotores) were never included as part of the investigation, we only went out to the communities and identified the people, and that was wrong!"

The promotores were not consulted to help review or help analyze the data from the surveys conducted by them. When the researchers reviewed the data results, they were surprised to see that depression was a higher concern than dementia or Alzheimer's. This was contrary to their initial hypothesis, so they questioned the promotores as to why the incidence of depression was higher.

One promotora believed that the researchers tried to impose their power and privilege on her community. Not only did they predetermine the outcome of the research, but they also assumed that the promotores and community were going to agree with their predetermined view. The promotores felt challenged and were surprised that their work would be undermined by the researchers, who were not acknowledging that there was a mental health issue in their community and, furthermore, not acknowledging such a high incidence of depression.

The promotora challenged the researcher.

The researchers can know a lot about papers, *pero el león no es como lo pintan*," she said.

The Mexican proverb or *dicho* "The lion is not as it's painted" signifies that when a lion is drawn or painted on a flat surface, we cannot grasp the force, strength, power, or potential danger it may pose on those around him. It refers to what may be hidden right in front of you.

Attempting to create a learning experience for the researcher, the promotora took the researcher to the main street of her historic village, asked the researcher to trust her, and said,

Close your eyes and don't be afraid" while she spun the researcher around three times.

When the researcher opened her eyes, she was looking across the Rio Grande on the U.S. side and facing the community.

"Do you have a beautiful home?" asked the promotora. The researcher responded by nodding yes. "If they could move your beautiful home right there!" She pointed to a corner lot in her community that was facing the Rio Grande. "Would you like to live here? Be sincere with yourself and don't try to convince me. Could you live here?" The researcher said, "No."

The promotora asked the researcher, "Do you think education is not at all important in our lives? Education," she raised her voice, "is most important!" She expressed a sense of agitation.

"Do you think that our people are not educated because they live in these conditions?" she continued. "*Ahora ya sabes por qué hay depresión.* Now you know why there is depression," she said in a defiant tone.

The promotora continued her story, stating she felt disheartened because not only did the researchers not see the results, but, more importantly, nothing led to anyone taking steps to remedy the mental health issue that was predominant in her community during or after the research was conducted.

Questions for Discussion

1. How does one integrate promotores into a research project effectively?
2. What is cultural humility? How would a researcher present the results back to the community based on actual findings?
3. Should promotores and community members receive the results of a study they participate in?
4. Why not include the promotores in the development of the proposal? Why not test a hypothesis? Predetermination is bad science.
5. Why not engage in CBPR to ensure the promotores and the community share perspective/expectations?

Recommendations and Best Practices

1. Provide opportunities for capacity building.
2. Share power and resources among partners involved in the research.
3. Consider whose priorities are valued more.
4. Researchers need put themselves in the position of the people and the lives they want to study.

5. As a researcher, have flexibility and adapt to the actual needs of the community. Don't predetermine. Be open to and prepared for unexpected outcomes.
6. The researcher should apply for additional funding to follow up, based on research findings.
7. Conduct focus groups before submitting grants.
8. Consider the long-term impact of the research on the community.

Comments from the Literature

Institutions need to consider how they will provide the scope of work, training, support, and supervision that Promotores need to be able to do this kind of community change work. (Latino Health Access et al. 2011)

A paper by Hilfinger Messias et al. (2013) presented the results of a randomized trial that examined the involvement of promotoras in a community-based participatory research project and documented the valuable roles, contributions, and knowledge of promotoras in their roles as partners in research related to health.

Considering the power of popular education for community empowerment, there are very few studies that document its effectiveness. Wiggins (2011), however, presents an extensive review of the literature, concludes that popular education is associated with empowerment for communities, and outlines structural conditions and steps that practitioners can take to increase the success of their work with communities.

Vignette 5

Principle: Integrity

In a rural New Mexico locality, two researchers from the same New Mexico University invested a great deal of time, with different results. One researcher working on a project engaged the community by collaborating with promotores, by incorporating staff and other stakeholders in the development of focus groups, by having them participate in the study, and by including the community and its members as coauthors of publications and/or copresenters at conferences.

One participant stated, “The researcher was not acting like she was above us, and we did not have to accommodate her; the researcher was accommodating us!”

The second researcher focused on an evaluation of a project but neglected to engage the community in the process and also failed to acknowledge the staff and promotores for their commitment and the hard work they invested on behalf of their community.

One of the administrators stated, “I had a sour taste in my mouth. It’s not that we do not want to share data, but we also want to benefit our community.”

The stakeholders felt that the researcher who did not credit the community members for their efforts in subsequent publications, manuscripts, and/or conferences did them a disservice by not sharing the credit. The individual researcher damaged his or her reputation and that of their institution. In this case, the promotores were dismayed that they could not benefit their community or bring about change by obtaining additional funding resources with the proof of the data that they had produced. Some of the promotores felt demoralized and dispirited by the experience.

As a result of the bad experience with the researcher who used the community for his or her own benefit, the community changed how it engages with research institutions. Members of this community participated in a CBPR training program, and with this experience they feel they are better prepared to continue engaging with research institutions. As it was stated by a program coordinator, “Now we know that we can advocate for ourselves, ask more questions, and work more closely with researchers.”

The fact that this community had a good experience with one of the researchers from the same institution helped the institution maintain its integrity and upheld the value of the researchers in community-based participatory research.

Questions for Discussion

1. How would you share data with the community?
2. How can non-University agencies work with promotores?
3. Should there always be a memorandum of understanding (MOU)?
4. How would you include stakeholders in publications and manuscripts? “The PIs have expectations of us [promotores]. We also have expectations of them.”
5. How does a research project benefit the community that participates in it?

Recommendations and Best Practices

1. Train researchers in how to work effectively with communities.
2. Incorporate CBPR in MOU development.
3. Develop training for investigators so they can learn that what they do has an impact on communities (negative and positive).
4. Provide focus groups.
5. Know that there is a ripple effect—beware of what, as a researcher, you leave behind.

Comments from the Literature

Promotores often mistrust the institutions they work for and feel exploited by them: “Sometimes institutions use Promotores, but they don’t believe in them. They see them as cheap labor. They say that if we provide food and speak in the community’s language, then people will come to the meeting and then they will be able to meet their program objectives.” (Latino Health Access et al. 2011, 42)

The difficulties in aligning the goals of researchers with the goals of communities, particularly communities where social and economic conditions are the main drivers of poor health conditions, are aptly addressed by Cacari-Stone and Avila (2012). They posit that researchers must move from minimizing to facing and addressing social conditions, by adopting an “action oriented approach [that works with communities] to advance social equity” (453). This approach to research with communities requires scientific integrity. Israel et al. (2001) emphasize the need to establish policies to enhance equity and reduce health disparities rooted in social conditions.

Vignette 6

Principle: Reciprocal Respectful Relationships

“Authentic relationship” has become the buzz term for both researchers and community stakeholders. But what does it really mean? In a recent plática with promotores, while we were reviewing this document, the meaning of “authentic relationships” was discussed. The group agreed that the term was overused and had lost its true meaning. In order to reestablish the connection between the words *authentic* (true) and *relationship* (bond), the group decided to define the term themselves. They defined “authentic relationships” as ones that were reciprocal (mutual) and respectful (humble, reverential). Consequently the title to this vignette was changed, and the following now reflects the perception of community stakeholders and researchers/universities.

As we were sharing an early breakfast at a local truck stop with community residents and a former nonprofit director, the conversation led to the topic of research in our communities.

A heated and passionate exchange was quickly sparked. “This gets to the point that is really, really important! [It] is the use of people!” said the former director. As administrators of nonprofits have assumed for many years, they believe they collaborate with higher educational institutions under the premise that they are in a partnership to benefit the community. “But, give me a break, most of the research is done because universities need the money!”

The perception of community residents and the former administrator is that funding guides the research, not the actual needs of the communities that are being studied. Higher education institutions are searching for funding availability to sustain themselves, not to identify solutions for marginalized communities.

As a result, many researchers benefit from the studied communities via grant funding, which pays for their salaries. As the former director stated in a distressed tone of voice and with teary eyes, “What is the ongoing cost that our community pays? And for what?”

Questions for Discussion

1. How do you develop an authentic relationship with stakeholders?
2. How does one raise the perception of some stakeholders about researchers/universities?
3. What are the costs and benefits of doing research to the communities?

Recommendations and Best Practices

1. Foster community involvement in all phases of research.
2. Include community in discussion and dissemination of reports/facts/data.
3. Allow community members to sit at the table to make sure the community’s needs are taken into account.
4. Show honesty, respect values and culture, listen.

Comments from the Literature

Changing institutional culture starts with the leadership and commitment of top decision-makers in an institution. By aligning the motivations and goals of their researchers, clinicians, and community members into a vision of a healthier population, Academic Health Centers' leadership will not just improve their own institutions, but improve the health of the nation—starting with improving the health of their local communities, one community at a time. (Michener et al. 2012)

A paper by Michener et al. (2012) addresses the need for institutions to change their culture in order to effectively address health disparities. Other researchers address the need to consider “insider-outsider” concepts (Yancey et al. 2006) or “inclusion/exclusion” (Cacari-Stone and Avila 2012) by understanding community values, norms, interests, and needs.

REFERENCES

- Brown P., Morello-Frosch R., Altman R.G., et al. 2010. Institutional review board challenges related to community-based participatory research on human exposure to environmental toxins: A case study. *Environ Health*. (9), 9-39.
- Cacari-Stone L., Avila M. 2012. Rethinking research ethics for Latinos: The policy paradox of health reform and the role of social justice. *Ethics Behav*. 22(6): 445-60.
- Cacari-Stone L., Hogue C., Cowboy L., McGough-Madueno A., Quinn-Hussein L., Chavez N., Wallerstein N. [In progress.] Barriers and facilitators to conducting health disparities research with communities: A qualitative study of an Academic Health Center in New Mexico.
- Estrada A.L. 2009. Mexican Americans and historical trauma theory: A theoretical perspective. *J Ethnicity in Substance Abuse*. 8(3): 330-40.
<http://dx.doi.org/10.1080/15332640903110500>.
- Hilfingier Messias D.K., Parra Medina D., Sharpe P.A., Treviño L., Koskan A.M., Morales-Campos D. 2013. Promotoras de salud: Roles, responsibilities, and contributions in a multisite community-based randomized controlled trial. *Hispanic Health Care Int*. 11(2): 62-71.
- Hyatt R.R., Gute D.M., Pirie A., Page H., Vasquez I., Delembert F. 2009. Transferring knowledge about human subjects protections and the role of institutional review boards in a community-based participatory research project. *Health Policy and Ethics*. 99:S526–S530.
- Institutional Review Boards in the U.S.-Mexico Border: Current Protocols and Practices (2010). United States -México Border Health Commission
http://www.borderhealth.org/files/res_1739.pdf
- Israel A., Schulz A.J., Parker E.A., Becker A.B., Allen A., Guzman J.R. 2008. Critical issues in developing and following CBPR research principles. In: Minkler M., Wallerstein N., Eds. *Community-Based Participatory Research for Health*. San Francisco: Josey-Bass; 47-62.
- Israel B.A., Schulz A.J., Parker E.A., Becker A.B. 2001. Community-based participatory research: Policy recommendations for promoting a partnership approach in health research. *Educ Health*. 14(2): 182-97
http://depts.washington.edu/ccph/pdf_files/EducforHealthIsrael.pdf.
- Johnson C.M., Sharkey J.R., Dean W.R., St. John J.A., Castillo M. 2013. Promotoras as research partners to engage health disparity communities. *J Acad Nutr Diet*. 113(5): 638-42.
- Latino Health Access, Visión y Compromiso, and Esperanza Community Housing Corporation.

2011. The promotor model: A model for building healthy communities. A framing paper funded by the California Endowment.
- Michener L., Cook J., Ahmed S.M., Yonas M.A., Coyne-Beasley T., Aguilar-Gaxiola S. 2012. Aligning the goals of community-engaged research: Why and how Academic Health Centers can successfully engage with communities to improve health. *Acad Med.* 87(3): 285-91.
- Resnick D.B., Kennedy C.E. 2010. Balancing scientific and community interests in community-based participatory research. *Accountability in Research.* 17(4): 198-210.
- St. John J.A., Johnson CM, Sharkey JR, Dean WR, Arandia G. 2013. Empowerment of promotoras as promotora-researchers in the Comidas Saludables y Gente Sana en las Colonias del Sur de Tejas (Healthy Food and Healthy People in South Texas Colonias) program. *J Prim Prev.* April; 34(1-2): 41-57.
- United States–México Border Health Commission. 2010a. Health research on the U.S.-México border: Promoting a binational agenda. A White Paper. http://www.borderhealth.org/files/res_2756.pdf. Accessed February 27, 2015.
- United States–México Border Health Commission. 2010b. Institutional Review Boards in the U.S.-México border: Current protocols and practices.
- United States–México Border Health Commission. 2014. Access to health care in the U.S.-México border region: Challenges and opportunities. A White Paper. http://www.borderhealth.org/files/res_2756.pdf. Accessed February 27, 2015.
- Wallerstein N.B., Duran B. 2013. Using community-based participatory research to address health disparities. *Health Promot Practice,* 7(3): 312-23.
- Wiggins, N. 2011. Popular education for health promotion and community empowerment: A review of the literature. *Health Promot Int.* 27 (3), 1-16.
- Witmer A. 1995. Community health workers: Integral members of the health care work force. *Am J Public Health.* 85:1055-58.
- Yancey A.K., Ortega A.N., Kumanyika S.K. 2006. Effective recruitment and retention of minority research participants. *Ann Rev Public Health.* 27:1-28.

APPENDIX 1: What is the IRB?

“NO research that involves human subjects, whether it is clinical or [in the form of](#) a survey or an interview, can begin until a research protocol is reviewed and approved (or, if applicable, exempted) by one of the Institutional Review Boards (IRBs). The Main Campus IRB is managed through the UNM ([or any other university’s](#)) Office of Research by the Institutional Review Board. Failure to comply can result in serious consequences for the principal investigator and for UNM and any other university. More importantly, non-compliance can potentially risk harm to participants.”

Refer to: <http://research-pdag.unm.edu/content/human-subjects-institutional-review-board-irb>

For history and more information about the Institutional Review Board refer to:
http://www.hhs.gov/ohrp/archive/irb/irb_introduction.htm

For a simple guide to the of IRB refer to: "Ethical Conduct of Research with Human Participants Training – Refer to

<http://www.ces4health.info/find-products/view-product.aspx?code=PSTZDJ5G>

This training is presented in PowerPoint to highlight the key principles of conducting research that follows State and Federal regulations the Institutional Review Boards apply. It is geared towards youth involved in research and is of benefit to anyone with a limited background in research.

APPENDIX 2: Sample Memorandum of Understanding between researchers and communities

Memorandum of understanding sample template: See

Source: https://accelerate.ucsf.edu/files/CE_Clinical_MOU_Template1.pdf

[Date]

I. Participants:

A. [County Name] Regional Medical Center, [County Name] Health Services

[County] Regional Medical Center is the safety-net health care delivery system for [County], anchored by the [#] bed full service county hospital. The system is a family practice based **federally qualified Health Center (FQHC)** staff model program that serves patients of all ages. [County] Services are nationally recognized for its family practice residency program. The [County] Medical Center primary care faculty and physician staff is composed of [#] [specialty type], and [#] [specialty type], approximately [#%] of whom are certified competent in [language] translation. The regional clinics have approximately [#] patient visits per month. Approximately [#%] of patients [age] come from households in which the primary language spoken is [language].

Contact Person: [Name], Title, Contact Information

B. [University Name], NIH-funded Center

The goal of the [University][Center Name] is to [study goal statement].

Contact Person: [Name], [Title], [Department], [School], [University], [Contact Info]

II. Project:

[Project Name] is conducted by [PI Name] and others from the [School at University] and is a [#]-year research study about [topic].

[Study rationale and brief description]

[Brief description of County participation and group assignment process]

III. Responsibilities:

A. [University] agrees to provide:

[For example, CE units to County providers].

[For example, assistance identifying liaison from University to work with County].

[For example, language appropriate educational brochures for Clinical MOU Template 1 UCSF CTSI Community Engagement Program Page 1 of 3 [For example, technology for the study].

[For example, ongoing technical assistance].

[For example, \$# for a total of \$#, based on: \$# at the start of the study and \$#

later based on performance criteria, created and agreed on by University and County].

[For example, a provider to facilitate assessments and send sending to University for diagnosis, also feedback on results to participants].

[For example, results of the study within # years].

B. [County] Medical Center, [County] Health Services agrees to the following:

1. Each clinical site assigned to [group A] will be responsible for providing the [intervention]; however, these costs should be more than offset by recharges to federal medical insurance for providing [examinations], [intervention], and [for example, education].
2. [County] will provide assistance with identifying a contact within the [County] which can provide [University] with assistance in mining necessary data for research purposes only. This information will not include any personal identifiers and will be reported only in aggregate form.
3. Each clinical site will provide space for 2 chairs for examination of [# of participants] based on an agreed upon schedule (e.g., once a month, once a week, evenings, weekends) that is best for the clinic.
4. Healthcare providers who agree to participate will:
Complete 3 written self-administered questionnaires (baseline, 12 months and 18 months) on their knowledge, attitudes and behaviors related to [area of study]. This will take 10 minutes for a total of 30 minutes and they will be completed and returned on-line or by regular mail.
5. For clinical sites randomly assigned to [group A], healthcare providers designated by [County] Medical Center, [County] Health Services will:
Participate in [study details].

[More study details].

Clinical MOU Template 1 UCSF CTSI Community Engagement Program Page 2 of 3
Clinical MOU Template 1 UCSF CTSI Community Engagement Program Page 3 of 3

6. For clinical sites randomly assigned to [group B], healthcare providers designated by [County] Regional Medical Center, [County] Health Services will:
Participate in [study details].

[More study details].

7. For clinical sites assigned to [group C], healthcare providers designated by [County] Regional Medical Center, [County] Health Services, will:

[Study details].

[Study details].

[Study details].

8. For Clinical sites assigned to [group D].

[Study details].

[Study details].

[Study details].

1. Based on the above, we agree to participate in this project. This agreement is valid from implementation date, to be determined by [University] and [County], and will last for [#] months thereafter. This agreement may be amended as mutually agreed upon. The Memorandum or Understanding is not a legally binding document but serves as an expression of partnership and commitment between [County] and the [University]. It is the responsibility of each party to notify the other in writing if there are any needed changes in the agreement or if the agreement needs to be terminated.

Concurrence:

[University] [County] Clinic

Date: _____ Date: _____

Appendix 3: Other Resources

Binational Research Ethics: All the reports (2000-2014) of the United States -México Border Health Commission. May be accessed at:

http://www.borderhealth.org/files/res_1739.pdf

Sample Agreements

1. Data sharing: See “NIH Data Sharing Policy and Implementation Guidance” Find at:

http://grants.nih.gov/grants/policy/data_sharing/data_sharing_guidance.htm

2. Example from: National Neighborhood Indicator Partnership. Find at:

<http://www.neighborhoodindicators.org/library/guides/key-elements-data-sharing-agreements>

3. Co-authorship: Author Agreement and Authorization Form: From North Western Undergraduate Research Journal. Find at:

http://groups.northwestern.edu/nurj/files/forms/author_agreement.pdf

4. Example of Students working with communities in research: Top 10 Ethical Considerations for Students Working with Community-Based Natural Resource Management Organizations. Find at:

<http://ewp.uoregon.edu/research/consortium-top-ten>