

Shiprock, New Mexico



Building Partnerships
for Health Disparity Research

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ACKNOWLEDGEMENTS

Dear Colleagues,

Thank you for contributing to an exciting dialogue on “Building Community Research Partnership for Reducing Health Disparities” on Tuesday, November 15, 2011. The University of New Mexico, NM CARES Health Disparities Center’s Community Engagement Core appreciates your time and contributions to making this a successful experience.

In appreciation for your time and participation, we will mail out a certificate of achievement. We hope you will join us in our efforts to seek out new and strengthen existing research relationships to conduct meaningful and applied research to promote health and well being for all New Mexicans. Thus, as a participant in the November dialogue, we are inviting you to become part of a community of researchers and to formally apply to be an Intercultural Health Disparity Scholar. The scholars are selected based on their commitment to reducing health disparities, promoting cross-cultural relationships, and developing intervention strategies that bridge community-based with science-based knowledge. Some of the benefits of being an Intercultural Health Disparity Scholar include:

- 1) Support to attend the National Health Disparity Conference to be held at the Crowne Plaza Hotel in Albuquerque, New Mexico on April 26-28, 2012;
- 2) Eligibility and support to participate in a week long training in Community-Based Participatory Research May 29-June 2, 2012 at the University of New Mexico in Albuquerque, NM; and
- 3) The opportunity for you and your colleagues to receive technical assistance and resources on topics (i.e. grant-writing for the National Institutes of Health, best practices and culturally congruent interventions for health promotion, translation research into policies) and to develop or adopt practical tools for putting community participatory research principles into practice and policy.

To sign up as an Intercultural Health Disparity Scholar, please complete the attached form and email to Lisa Cacari Stone at lcacari-stone@salud.unm.edu or copy the text of the form into an email by April 5, 2012.

We look forward to following-up with you regarding key recommendations you made which you will find summarized in the attached minutes from the meeting. Additionally, we will continue to sponsor training and networking opportunities as part of our NM CARES Health Disparity Center.

Again, thank you for your participation in the training and look forward to working with you.

Sincerely,

Lisa Cacari Stone
Nina Wallerstein
Clarence Hogue Jr.
Lucinda Cowboy
Alison McGough-Maduena

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INTRODUCTION: BRIEF HISTORY OF ETHICS IN CONDUCTING HEALTH DISPARITIES RESEARCH

Dialogue as a Tool: Dr. Lisa Cacari-Stone, Director of Community Engagement Core/NM Cares Health Disparities Center

Why is dialogue important for doing research with communities?

Dialogue with communities is important in building community-academic partnerships for engaging in health disparity research based on intercultural leadership, trust, guiding principles, and mutual terms and conditions of agreements.

Research in communities has come a long way from the abuses inflicted mostly on America's minority populations. Practices by researchers are now studied, reviewed and approved by regulating bodies such as an **institutional review boards (IRB)**, also known as an **independent ethics committee** or **ethical review board**. These committees have been formally designated to approve, monitor, and review biomedical and behavioral (social science) research involving humans.

Brief history of distrust between communities and academic researchers

We acknowledge that communities and ethnicities have been abused, misinformed and misled in their role and participation in research. Before 1974 and the creation of IRB committees most research was conducted with little thought to the people involved and used minorities as guinea pigs.

Examples of research abuse among communities:

- 1932-1972 Tuskegee Syphilis Experiment
- 1890-1930 immigration policies

Post 1974:

- Parachuted onto communities by pulling data and not sharing results with communities
- No investment back to the communities

- Research for the sake of research or research objectives that don't match the needs of communities
- 1990-1992—Havasupai Tribe \$50 M lawsuit against Arizona State University for misuse of blood samples

What is UNM's vision?

- Community-Based Participatory Research (CBPR) model working with communities to inform, provide solutions for family wellness, culture and language preservation/restoration.
- Increase access to care
- Training of new researchers from racial ethnic & other under-represented communities
- The University of New Mexico Health Science Center (UNM HSC) is growing and is recognized as the national leader in research with communities.
- UNM HSC continues to work on collaboration efforts externally with Community Organization and internally with Faculty and students.

FRAMEWORK FOR CONDUCTING HEALTH DISPARITIES RESEARCH *WITH COMMUNITIES*

Based on principles of Intercultural Communication/Leadership and Community-Based Participatory Research, the NM CARES seeks to foster institutional reflection and change and cultivate partnerships and capacities for UNM to conduct health disparities research with and across diverse communities in New Mexico. The Guiding Framework depicts how the needed community and institutional changes can happen to overcome contextual barriers (discrimination, socio-economic inequity) when the research relationship and process are built upon principles of Intercultural Partnership and CBPR. Using this framework as a basis for engaging with communities, the NM CARES HD (Community Engagement Core) will be identifying and contacting academic and community partners to become Intercultural Health Disparity Scholars.

Goals of the Community Engagement Core

The goal of the Community Engagement Core (CEC) is to build relationships, trust and create partnerships between *Researchers* and *Community* in order to support research towards eliminating health disparities and inequality and improve health equity and fairness in diverse communities. As part of the NM CARES HD we seek to support institutional reflection and change, and enhance the partnerships and capacities of UNM to conduct health disparities research with — and across diverse communities in New Mexico

Our Vision

In order to strengthen research aimed at eliminating health disparities, NM CARES HD will focus on the following three intervention-based principles:

1. Community partnering, through Community-Based Participatory Research (CBPR).
2. Multilevel interventions within a cultural and social context; and
3. Translating scientific and community-based evidence into disparities interventions (practice and policies)

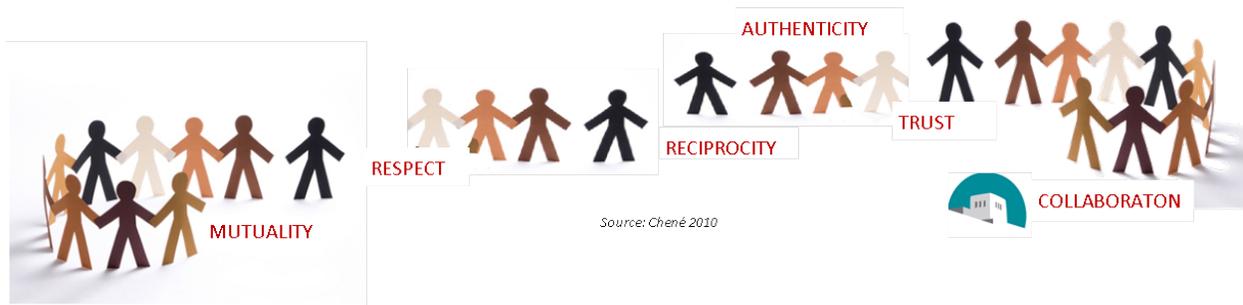
Our Aim

The CEC has the following four aims:

1. To create multi-directional partnerships between academic *Researchers* and *Community* constituents (clinicians/providers, policy makers, community organizations, and community members);

2. To promote academic researcher reflection and organizational assessment of barriers and bridges to community engagement, and to develop action strategies and best practices for enhancing community trust, and university/community partnerships;
3. To develop co-learning and mentoring opportunities through allies of “Intercultural Health Disparity Scholars” and summer co-learning One-Day Institutes;
4. To translate and share findings with our community partners to enable practice, program, and policy interventions.

Our Principles

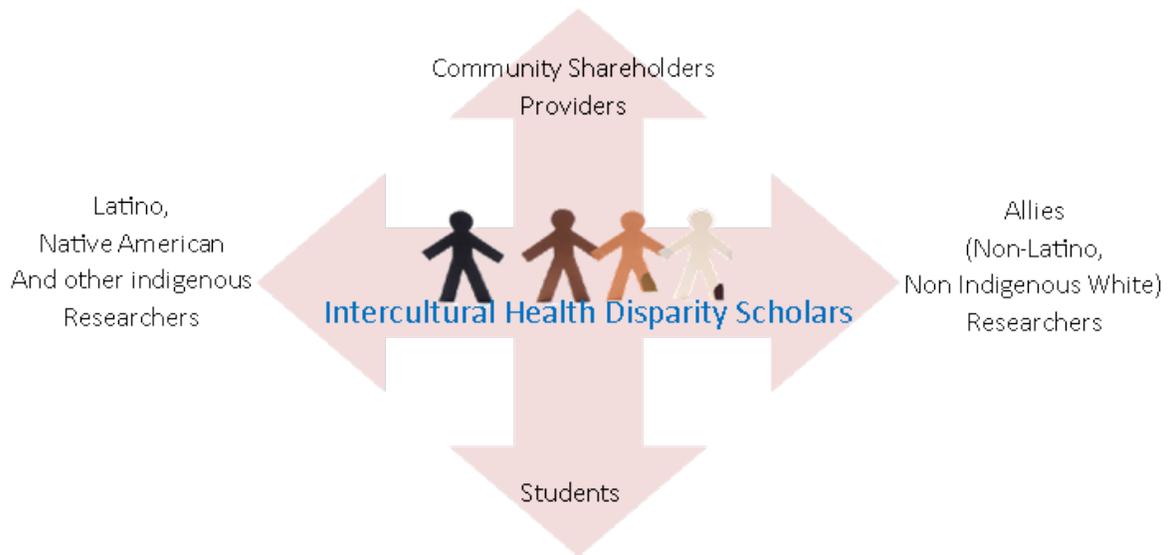


See Appendix 2 and Appendix 3.

Our Approach

Intercultural Health Disparity (IHD) Scholars and Dialogue

Teams of IHD Scholars are being recruited from within New Mexico’s diverse communities and will include indigenous and non-indigenous academic researchers, students and other community constituents (clinicians/providers, community members, traditional healers, local, state, and tribal policy makers). Furthermore, IHD Scholars will be selected for their commitment to reducing health disparities, promoting cross-cultural relationships, and developing intervention strategies that bridge community-based with science-based knowledge.



The Intercultural Community-Based Participatory Research Model below describes how the community and institutional changes can happen while overcoming barriers (discrimination, socio-economic 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. This framework aims to increase capacities of institutions and communities to work together and conduct mutually beneficial research that Reduces Health Disparities and Increases Health Equity. See: <http://hsc.unm.edu/programs/nmcareshd/cec.shtml#tabs1-guiding>

INTERCULTURAL COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR) MODEL



CONTINUUM OF RESEARCH

A - Research with Communities

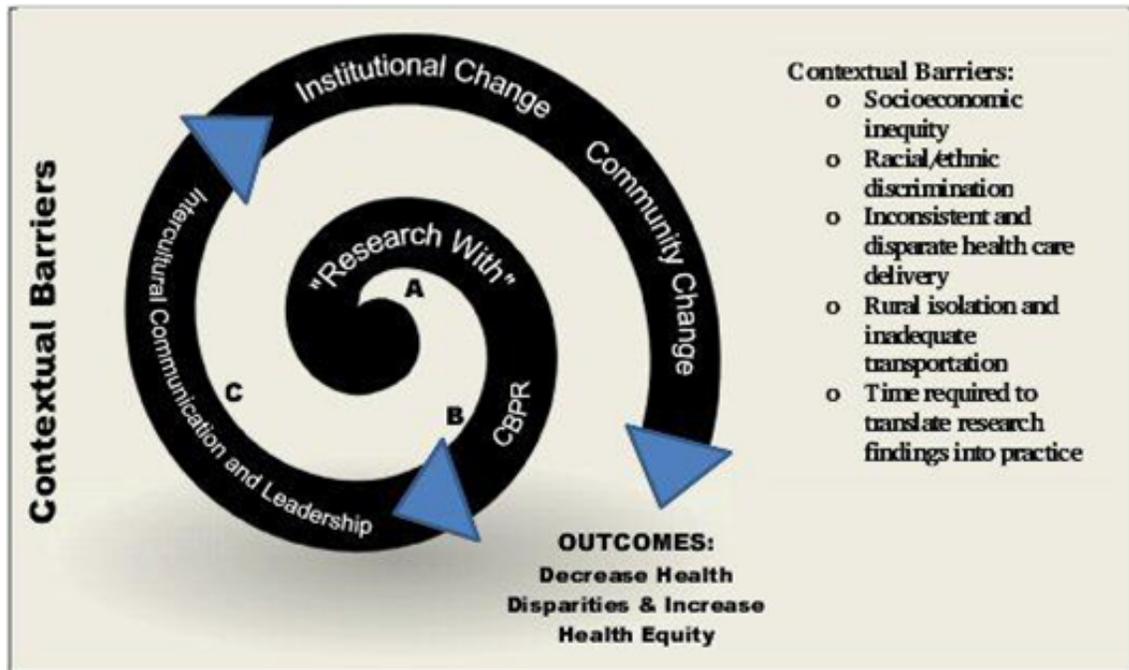
In order to move towards institutional and community change, dialogues between academic and community members are needed. The focus of the on-going dialogues should be on “how” we shift our thinking about doing community research from using an “on/in” approach to a “with” modality. The figure above illustrates 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 co-learning and capacity building process among all partners. All research findings and knowledge gained is shared with all partners. CBPR involves a long-term process and commitment from both Researchers and Community. *Source: Israel et al. 2003, pp. 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 each other 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.
- Both partners step into a mediator role “for the community but not against the institution.”



- Engage in intercultural communication based on:

Anticipated Outcomes

This framework aims to increase capacities of institutions and communities to work together and conduct mutually beneficial research that Reduces Health Disparities and Increases Health Equity in New Mexico.

PREAMBLE

The Facilitator's Guide, as used in Shiprock (Diné Nation), resulted from a continued process that involved developing a partnership between the Community Engagement Core (CEC) of the University of New Mexico and the Shiprock community. This relationship-building joint journey started early in 2011 by two CEC community engagement liaisons, Lucinda Cowboy and Clarence Hogue, who attended several RCFW committee meetings of the Restoring and Celebrating Family Wellness Committee (RCFWC) to introduce and explain NMCARESHD goals and aims. During these meetings Clarence and Linda introduced the concept of the *Intercultural Healthy Disparity (IHD)* Scholars and invited anyone interested to apply. The committee members helped with recruitment of IHD Scholars for the first community dialogue/training that was planned for November 2011. On November 15, 2011 the CEC facilitated a one-day dialogue/training on "Building Partnerships for Health Disparity Research" at the Shiprock Indian Health Services- Northern Navajo Medical Center building.

The Facilitator's Guide that follows presents the instructions that the facilitators of the November 15, 2011 meeting used, and is meant to guide others who want to have a similar dialogue with their communities about how to establish working relationships with researchers that respect traditions, knowledge, and styles of communication of indigenous communities.

For a detailed summary report that was co-created and approved with the community partners from Shiprock please see:

http://hsc.unm.edu/programs/nmcareshd/docs/shiprock_summary_report.pdf

TRAINING CONTENTS, FACILITATOR GUIDE COMPONENTS AND TIMELINE

ONE DAY COMMUNITY TRAINING

“Building Partnerships for Health Disparity Research”

9:00 – 10:00 Introduction to Training Day

Preparation: Review Handouts (See Appendices 2 and 3). Prepare a flip chart with the frame wording and the objectives. Think of a creative way for participants to introduce themselves. Perhaps they can say one thing that brought them to the training session. Think about what type of language to use throughout the day that will be helpful to both sides of the partnership, the institution, and the community.

Materials:

- Flip Chart Paper
- Markers
- Power point presentation slides on the history of HD research, NM CARES HD background, and CEC Aims
- Handouts of the CEC Intercultural CBPR model and the “On/In/With” continuum of research model and NM CARES HD one pager to provide background

Welcome: Thank everyone for attending.

Introductions: Presenters, facilitators, and participants will introduce themselves.

(NOTE: Developing some slides on health disparity research might be useful. The following link leads to slides developed by Dr. Cacari-Stone: “Eliminating Health Disparities: The Promise of Naming & Moving Research & Action”

LINK: hsc.unm.edu/programs/nmcareshd/cec.shtml#tabs1-comm_trainings (under the “Health Equity Policy Making” tab)

Overview: Provide the context for the training and present the frame for the day

Setting the Frame for the Day: Building a partnership for doing research that is based on intercultural leadership, mutuality, trust, and guiding principles.

Objectives:

- Create a space that promotes safety, bonding, and bi-directional intercultural learning among the participants
- Present an intercultural CBPR model that values doing research “with” communities

- Develop action-oriented research themes that lead to the development of the Intercultural Health Disparities (IHD) Scholars Teams
- Establish new terms of research engagement to foster trust within community-academic partnership.

Create Group Expectations and Agreements:

- Guide the participants in discussion to develop agreements that will help them feel safe to share their experiences and insights throughout the day. Also include expectations of participants for the day.

Overview of history of health disparity research:

- Share a historical overview of how health disparities research has evolved and what the role and value of research is, specifically intervention research.
- Guide a discussion of positive and negative research experiences using “deep listening”. Divide the group into smaller working groups. Ask the following questions (each group answers both questions. After 15 minutes reconvene the groups for debriefing).

Questions:

- 1. In your experience what have been the barriers to doing research in your community?
- 2. What are facilitators/ideas for improving research to reduce Health Disparities?

Brief overview of the NM CARES HD:

- Briefly touch on Center goals (eliminating disparities), role of the CEC, and aims. Provide enough information to give participants a sense of “who we are.”

10:00 – 10:50 Positive and Negative Research Experience, Buzz Groups, and Building Partnerships through Effective Intercultural Communication

Preparation: Review handout content on intercultural communication concepts. Prepare flip chart with three columns to record responses: listening skills, facilitators, and barriers (The term *Barriers* may have undertones of historical mistrust so be prepared to discuss these issues.)

Materials:

- Handouts on intercultural communication concepts Appendices 5, 6 and 7
- Flip Chart Paper
- Markers

Objectives:

- Participants will answer the following questions:
 - What do you think helps with doing effective partnered research?
 - What do you think hinders doing effective partnered research?
 - What ideas do you have about how research could reduce health disparities?

- Participants in Shiprock wanted to understand the definition of health disparities before going any further, and doing so may be a good starting point for this portion of the conversation.
- Participants will hear from one another about why doing health disparity research matters
- Participants are introduced to some key Intercultural Communication concepts in developing effective partnerships:
 - Deep listening
 - Mutuality
 - Leadership
- Participants will reflect on their experiences with doing community research

10:50 – 11:00 Morning Break

Preparation: Purchase healthy snacks

Materials: Morning snacks, handouts, slides, projector.

11:00-11:50 Deep Listening Exercise (Appendix 6)

Introduction and Instructions (5 minutes): This activity will provide an opportunity for all participants to share their thoughts about doing health disparity research and allow participants to assess how well we listen to each other. We will debrief the exercise at the end and have people share what they learned from one another.

Listening Exercise (10 minutes): The participants will select a partner and form pairs. Participants should try to pick someone who they do not know very well. The pair will decide who will be the listener and the speaker. For the first 3 minutes, the speaker will share his/her thoughts about what they have seen or how they have experienced health disparities at a personal or community level (or both). The listener's role is to JUST LISTEN and not interrupt with questions or make any noise. When the time is up, neither person can comment about what just took place and what was said. The pair will immediately switch roles, and the new speaker will then have another 3 minutes to tell his/her thoughts on the topic. Again the listener's role is to listen, nothing else. After the second speaker finishes, neither person can talk about each other's stories. Next, using the same process the pairs will address the following question for 3 more minutes each: What ideas do you have about how research could reduce health disparities?

Pair Debriefing (5 minutes): Once this time is up, the pair can now share anything they would like to with one another.

Group Debriefing (10 minutes): Ask the participants what they learned from one another. What did they think about the process? What made it easy or difficult to do? In discussing this particular topic/issue, what did you learn about your own listening skills? How important is having good listening skills to strengthen communications and to build relationships? What interesting thing did you hear in discussing this particular topic/issue?

Record the responses on the flip chart: Use the responses to record three columns, one for what they thought about their listening skills, another for the facilitators, and another for the barriers. List for main themes that emerge.

Connect to key concepts/principles (20 minutes): To introduce the following key concepts in building effective partnerships with communities:

- Listening is a basic requirement to building relationships and is at the root of effective partnering.
- Valuing and taking each other seriously
- Mutuality
- Being a good researcher can also mean being a good leader

Transition: Explain that the observations that the participants listed from the deep listening exercise will help set the tone for the rest of the day's learning.

In hearing about your experiences, particularly some of the negative ones, how can we begin to shift our thinking towards improving ways research can happen?

11:50 –12:20 Short Presentation on CBPR – Challenges and Successes

Preparation:

Materials:

- Tribal Participatory research
- Handouts on CBPR Principles & Decolonized Research Principles (Appendix 2 and Appendix 3)
- PowerPoint slides

Objectives:

- Participants will be introduced to a research approach that values community input and participation.
- Participants will explore a new research paradigm.
- Participants will see where on the research continuum they feel their community is.

Presentation (20 minutes):

- On/In/With Model
- Define CBPR – history slides “ Community -Based Participatory Research (CBPR) and Reducing Health Disparities” NM CARES health Disparities Center Community Engagement team

LINK: hsc.unm.edu/programs/nmcareshd/cec.shtml#tabs1-comm_trainings (Under Health Equity Policy Making tab)

- Introduce Principles – include tribal principles
- Long term commitment – challenging process

- Work in Jemez, Ramah, and other communities (i.e. the Family Listening Project)
- Steps to CBPR
- Outcomes- added value of CBPR
- Ethical protocols – what it means

Discussion (10 minutes): Participants will provide any feedback and ask questions. Have participants reflect on the “added” value of CBPR.

12:20– 1:00: Lunch

Preparation: Order lunches

Materials:

- Lunch for participants and facilitators

1:00 –1:15: Refocus and re-energize the participants

Preparation: Find a good icebreaker on the Internet, or one you have used successfully before.

Materials:

- Determine what items you will need for your icebreaker.

1:15 –2:00 Guiding Principles in Partnerships

Preparation: Review handouts and exercises (see Appendices 2 and 3)

Materials:

- Flip Chart Paper
- Markers
- Principles Handout (see appendix) (same as above)

Objectives:

- Identify guiding principles present in partnerships
- Understand how these principles shape the research process

Participants will answer the following questions:

- What are some guiding principles that would shape how you approach working in research partnerships?
- Why are those principles important to you?
- What concerns you the most about going into a partnership?

Introduction (3 minutes): Guiding principles help how a research partnership is formed.

Guiding principles exercise (10 minutes):

This exercise will help you think about what principles you bring to partnerships and why acknowledging each other's principles is important through reflexivity and self-awareness. Many of you have worked in partnerships, either with research or organizing.

In pairs, the group discusses: "What are some guiding principles that would shape how you approach working in research partnerships? Why are those principles important to you? What are you most concerned about in going into a partnership?"

Large group debrief and discussion (25 minutes):

Bring the group back together.

Ask people to share and write their responses up on flip chart paper (create two columns: guiding principles/concerns).

Be sure to hear from both academic researchers and from community/agency partners.

In guiding the discussion, try to have the participants focus on the following areas:

- Concerns for partnerships
- Strengths they bring
- What they hope to gain from one another

As people in the group are sharing, identify shared threads and commonalities that come up, as well as the differences. Write these on the flip chart as well.

PROMPTS: If people seem confused or have a hard time getting started, ask them "What's important for you when thinking about starting a new partnership?" or "What matters most to you when starting a new partnership about how you would work together?"

EXAMPLES: People may say things like:

- Trust
- Communication
- Recognition of power dynamics within partnerships and attempts to build equity, challenge privilege
- Community control over data
- Making sure the research doesn't harm the community being researched

Summary of Themes (5 minutes): Choose from this list as applicable and/or develop new examples that the group comes up with.

- Guiding principles are central to CBPR
- There isn't uniformity of values/principles
- Different research partners have different priorities and values
- There are multiple ways to solidify the values anchoring the research partnerships
- It's important for partners to have direct and honest conversations about values.
- Values and how they guide our work may need to be revisited at different points during collaboration.

Transition: Bridging CBPR principles and the group’s guiding principles with practice. Partnerships are always evolving so guiding principles need to be revisited continually.

2:00 – 2:15 Afternoon Break

Preparation: Purchase healthy snacks

Materials:

- Afternoon snacks

2:15 –3:00 From Principles to Practice – New Ways of Working Together

Materials:

- Flip Chart Papers
- Markers
- Handout on Community Engaged Research Protocols (Appendix 4)

Objectives:

- Establish terms of engagement for doing community research based on the guiding principles identified as well as the CBPR principles, to guide future research partnerships.
 - Include discussion of agreements that could be explicitly shared and not taken for granted.
- Develop key components of what would support an academic-community partnership agreement.

Introduction: Begin this section by asking the group, “What are some of the research opportunities that could address health disparities in your community?”

Large group discussion: Guide the participants through a discussion on what will determine the community’s level of engagement in the research process by asking the following questions. Tell the group to keep in mind what a community driven research would/could look like:

- Agreements - How are we in relation with each other?
- Conditions - To do my/our best work around research, what conditions need to exist between the university and the community? For outside institutions and agencies to conduct research in my/our community, what conditions need to exist?

Record the responses on flip chart paper.

Ask the group to share examples of ways they have established and manifested their guiding principles and the CBPR principles in research partnerships (or ways they might want to try if they haven’t yet been involved in such work):

- Informal ways, relational
- Structural ways, i.e. Memoranda of Understanding (MOUs), advisory boards
- Some combination of both

3:00 – 4:00 Setting Priorities and Next Steps

Materials:

- Evaluation Form

Closing and Evaluation:

- Objectives: Re-emphasize that the purpose of today's training is to begin the formation of the IHD Scholars Team and what will be the key steps in forming the teams and also to begin listing priorities areas that the team would like to address.
- Discussion of next steps

Do a plus/delta to capture what we should keep and what needs to be changed as part of the day's activities.

Large group discussion: What will be the next steps and where do we go from here?

Consider:

- What language that is common to all of us should we be using?
- What specific ideas on research projects can we develop collaboratively
- What structures and agreements do we need to have in place to prepare for the work that we will need to do together?
- Present information about the IHD scholars and the co-learning institutes and ask if anyone in the group wants to be a part of this.

Thank everyone for attending training today.
Ask participants to complete the evaluation form.

Evaluation (Appendix 7)

APPENDICES

Appendix 1: Resources for Community Trainings

Source: http://hsc.unm.edu/programs/nmcareshd/cec.shtml#tabs1-comm_trainings

Historical Trauma

Dr. Maria Yellow Horse Brave Heart addresses: Building research capacities to bridge cultural and indigenous knowledge and practices with empirically supported theories and interventions. Dr. Brave Heart introduces the concept of Historical Trauma and its impact on the health of American Indian/Alaska Native children, youth and their parents. She also provides an overview of the Historical Trauma Unresolved Grief Intervention (HTUG) as an approach to addressing intergenerational massive group trauma healing.

Intercultural Communication

Roberto Chene, provides training for those that function in multicultural settings and the focus of the training was develop across racial and cultural allied relationships, intercultural leadership and creative conflict resolution skills. The training focused on guiding principles and strategies for developing mutually beneficial intercultural relationships and partnerships for conducting health disparities with communities.

Community-Based Participatory Research (CBPR)

Dr. Nina Wallerstein provides sessions on CBPR and related approaches, i.e., Participatory Action and Community-Engaged Research a “collaborative approach that equitably involves all partners in the research process with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities”(Kellogg Foundation). CBPR is an overall orientation, not a method that fundamentally changes the relationship between researchers and researched. The module explored how CBPR intersected with indigenous knowledge and methodology, including the challenges for academics and community members to co-construct knowledge for improved community health.

Understanding Community Engagement

Clarence Hogue provides training on approaches to community engagement for researchers on developing personal relationships with leaders or other representatives of communities, understanding the needs, desires, and characteristics of that community, and making your research needs more understandable and acceptable to these communities.

Health Equity Policy Making

Dr. Lisa Cacari Stone provides training for community leaders, health advocates, university researchers, health providers and policy makers on “tools, methods and processes for evidence informed policy making.” Her work supports the premise that “good policy follows good science” Supporting the policy research skills development of multi-cultural leaders and communities most burdened from health inequities is a step-towards from “discovery to practice and policy-based solutions.” She also provides consultation on Latino and border health research.

Appendix 2: Key Principles of CBPR

Source: Israel, B. A., Eng, E., Schulz, A. J., & Parker, E. A. (2005). Introduction to methods in community-based participatory research for health. In B. A. Israel, E. Eng, A. J. Schulz & E. A. Parker (Eds.), *Methods in community-based participatory research for health* (pp. 3-26). San Francisco, CA: Jossey-Bass.

1. Acknowledges community as a unit of identity.
2. Builds on strengths and resources within the community.
3. Facilitates a collaborative, equitable partnership in all phases of research, involving an empowering and power-sharing process that attends to social inequalities.
4. Fosters co-learning and capacity building among all partners.
5. Integrates and achieves a balance between knowledge generation and intervention for the mutual benefit of all partners.
6. Focuses the local relevance of public health problems and ecological perspectives on multiple determinants of health.
7. Involves systems development using a cyclical and iterative process.
8. Disseminates results to all partners and involve them in the wider dissemination of results.
9. Involves a long-term process and commitment to sustainability.

Appendix 3: Guiding Principles for Decolonizing and Indigenizing Research

Source: Walters, K.L., Stately, A., Evans-Campbell, T., Simoni, J.M., Duran, B., et al., (2009). "Indigenist" collaborative research efforts in Native American communities. In A. R. n (Ed.), *The field research survival guide*. (pp. 3-26). New York, NY: Oxford University Press.

1. Reflection

True partnerships begin with reflection upon the privileged statuses from which most partners operate and the emotionally difficult task of acknowledging the pain of Native communities and developing empathy.

2. Respect

Research partners must value and prioritize indigenous epistemologies, knowledge, cultural protocols, and healing practices.

3. Relevance

The community should contribute to defining research problems and strategies, which should respond to their own self-identified needs and concerns.

4. Resilience

All aspects of the research must acknowledge the community's strengths and resilience.

5. Reciprocity

The partnership should be collaborative and mutually respectful with knowledge exchanged in both directions.

6. Responsibility

Research partners are obliged to enhance community capacity to conduct Indigenous and Western research, disseminate research findings in culturally meaningful ways, and anticipate the implications.

7. Retraditionalization

Traditional knowledge and methods must be actively integrated into the formulation of the research questions and the process of scientific inquiry.

8. Revolution

Research partners and community members must actively seek to decolonize and indigenize the research process to transform science as well as themselves, their communities, and the larger society for the betterment of all.

Appendix 4: Samples of Community Engaged Research Protocols

Community Engaged Research Protocols

When beginning to form a research relationship, agreements can be created to provide structure to the establishment of a relationship between your community and research partners. Explicitly outlining your approach to research will ensure the respect of all partners. The research process includes: developing the research questions; determining research methodology; the collection, analysis, and interpretation of data; and the dissemination of the experiences and results. The following are key areas covered by documents drafted by the CBPR Research for Improved Health Study Team to ensure mutual respect and knowledge sharing among partners. The areas addressed by the documents are:

- Appropriate Research Approvals
- Human Subjects Protection/ Community Protection
- Data Dissemination and Ownership
- Research Processes

Code of Ethics and Integrity

Outlines a set of mutually developed principles, obligations, and procedures that is used to guide all involved groups to achieve the goals and objectives of the partnership through out all phases of the research process. Suggested areas to specifically addresses:

- Responsibilities of
 - o Principal investigator
 - o Executive Committee
 - o Community Advisory Board/Tribal Research Teams
 - o Community-Academic Partners
- Mission and Vision
 - o State mission statements of all involved partners along with their visions
- Project Values/Principles
 - o Suggested Areas to address:
 - Promote Collaboration
 - Good Science
 - Accountability and Transparency
 - Equalizing Power
 - Ensure Utility of Research for Community
 - Support Research Partners

SOURCE: CBPR Research for Improved Health Study Team. 2011. Project Code of Ethics and Integrity, Research for Improved Health: A National Study of Community-Academic Partnerships . Project Protocols, National Congress of American Indians Policy Research Center. From: NARCH V (Indian Health Service/NIGMS/NIH U261HS300293 2009-2013), a partnership between the National Congress of American Indians Policy Research Center (Sarah Hicks, PI); the University of New Mexico Center for Participatory Research Institute (Bonnie Duran, PI); and CBPR projects nationwide. Found at: (<http://narch.ncaiprc.org/documentlibrary/2011/08/NCAI-UNMUW%20NARCH%20V%20Research%20for%20Improved%20Health%20Project%20Code%20of%20Ethics%20and%20Integrity.pdf>)

Protocol for Student Involvement

Clearly outlines expectations around Student involvement, access to data, review of presentations and publications, and how the established partnership core values are concretely applied within their relationship with the project. Provides specific guidelines for:

- How students are brought on to team
- How students must go about conducting independent analysis of project data and use of other materials
- Other requirements including the review of and agreement to uphold project core values and expectations outlined in other protocol and guideline documents.

SOURCES: CBPR Research for Improved Health Study Team. 2011. Protocol for Student, Fellow, Pre-Doc, and Post Doc Involvement in Research Team. Project Protocols, National Congress of American Indians Policy Research Center. From: NARCH V (Indian Health Service/NIGMS/NIH U261HS300293 2009-2013), a partnership between the National Congress of American Indians Policy Research Center (Sarah Hicks, PI); the University of New Mexico Center for Participatory Research Institute (Bonnie Duran, PI); and CBPR projects nationwide. Found at: <http://narch.ncaiprc.org/documentlibrary/2011/08/NCAI-UNMUW%20NARCH%20V%20Research%20for%20Improved%20Health%20Protocol%20for%20Student%20Involvement%20in%20the%20Research%20Team.pdf>

Publication Guidelines

Research involves the sharing of information and experiences in both formal and informal settings. It is useful to a multidisciplinary partnership to have a clear outline of how to approach the creation and use of “publications” related to the research being conducted and addresses:

- Publication Protocol
- Authorship- Criteria/Responsibility
- Role of the PI in publications: It is also useful to have a set of principles outlined to guide the manuscript development and publication process and address:
- Anonymity, Individual and Partnership
- Privacy and Confidentiality
- Respect

SOURCE: CBPR Research for Improved Health Study Team. 2011. Publications Guidelines, Research for Improved Health: A National Study of Community-Academic Partnerships. Project Protocols, National Congress of American Indians Policy Research Center. From: NARCH V (Indian Health Service/NIGMS/NIH U261HS300293 2009-2013), a

Communication Guidelines

In addition to sharing information through publications research often involves both written and verbal communication around research activities and subject matter. It is useful to have a document that may be used as a guide to follow when developing communication materials. Having a checklist to consult will ensure that materials reflect and embody the project values. Additionally the document may provide:

- Standard statements of
 - o Project Name
 - o Project Description
- Checklist of Consideration similar to that devised for publication guidelines

SOURCE: CBPR Research for Improved Health Study Team. 2011. Communications Guidelines and Checklist, Research for Improved Health: A National Study of Community-Academic Partnerships. Project Protocols, National Congress of American Indians Policy Research Center. From: NARCH V (Indian Health Service/NIGMS/NIH U261HS300293 2009-2013), a partnership between the National Congress of American Indians Policy Research Center (Sarah Hicks, PI); the University of New Mexico Center for Participatory Research Institute (Bonnie Duran, PI); and CBPR projects nationwide. Found at:
<http://narch.ncaiprc.org/documentlibrary/2011/08/NCAIUNMUW%20NARCH%20V%20Research%20for%20Improved%20Health%20Communications%20Guidelines.pdf>

Appendix 5: Cultural Competency and Intercultural Collaboration Training
Author: Roberto Chené, Consultant, Intercultural Communication,
Leadership and Conflict Resolution, rchene@comcast.net

Mutual respect is what sustains extraordinary group efforts.
Leaders create an atmosphere of trust and human dignity.
They nurture self-esteem in others.
They make others feel strong and capable.
Kouzes and Posner, The Leadership Challenge

Mutuality

- Mutuality is at the heart of interculturalism.
- Interculturalism is primarily about building relationships.
- Time must be taken to listen to our differences in building relationships. This is indispensable.
- Differences have to be approached directly. No assumptions can be made about anyone.
- The goal is to appreciate differences as differences, nonjudgmentally.
- Trying to work together without taking the time to discover the richness of our diversity increases the possibility for conditioned historical conflict to assert itself.
- A sense of everyone's life stories is needed to illuminate different points of view.
- In listening respectfully and accepting our differences, our similarities are discovered.
- At the heart of cultural diversity is the idea that each cultural group has valued and knowledge that others need. No one person or culture is whole without relationship to other people and cultures.
- No one culture should be dominant to the exclusion of other cultures. When dominance occurs, balance is lost which is essential to wholeness.
- The ultimate understanding of human diversity is that everyone is unique, yet interconnected with everyone else in the human community.

A Mutuality Model

1. Listen with respect.
2. Share accurate histories.
3. Appreciate oneself: Self-esteem.
4. Appreciate others: Esteem others.

Appendix 6: Deep Listening: Outcomes

**Author: Roberto Chené, Consultant, Intercultural Communication,
Leadership and Conflict Resolution, rchene@comcast.net**

- Reminds us to slow up
- Models the value of focused attention · Practice reciprocity
- Experience nonjudgment and sense of equality
- Enjoy mutual discovery of differences and commonalities
- Lowers fear and discomfort level
- Establishes some sense of safety and trust
- Explicit expression of community: not left to chance
- Practice in bypassing stereotype and bias
- It's about the other, not about you
- Experience sense of being taken seriously
- Establish relationship roots for harder work later on
- Promotes peace making
 - We experience the opposite of oppression and exclusion
 - Certain amount of personal transformation
 - Sets the tone for building on commonalities
 - Generates energy for change

Appendix 7: Cultural Competency and Intercultural Collaboration Training
Author: Roberto Chené, Consultant, Intercultural Communication,
Leadership and Conflict Resolution, rchene@comcast.net

Guidelines for Creating Multicultural Communities and Coalitions

- Truly integrated communities are rare. Most of what we call integration is actually a norm of racial or ethnic mixture.
- Integration begins to happen as differences are acknowledged and respectfully understood. Trust is built on the acceptance of differences.
- The key to working together toward a common goal is to realize that we discover our similarities as we accept our differences.
- The challenge is to focus positively on diversity and on what each of us can contribute to a new way of building intercultural relationships.
- The eruption of conflict often results when the group does not take the time to accept differences and to build trust.
- The way to empower the group to build an intercultural relationship is to be willing to look at the real differences in a direct and non-blaming manner.
- Building an intercultural community requires that each member or group commit itself to the welfare of others and to the common good of the whole.

TIME
LISTENING
PARTICIPATION
VISIBILITY
VALIDATION
EQUALITY
CULTURAL SELF-AWARENESS

Appendix 8: Evaluation Form

“Building Partnerships for Health Disparity Research”

One Day Community Training

Las Cruces, NM

Thursday, November 15, 2011

EVALUATION

Please review the following list of objectives and give some thought to what you knew before, and what you learned here today. Circle the number that best represents your level of knowledge and skills before and after the training.

RATING SCALE: 1 = LOW 3 = MEDIUM 5 = HIGH

Before Training	LEARNING OBJECTIVES	After Training
1 2 3 4 5	Identify components of an intercultural CBPR model that values doing “with” communities.	1 2 3 4 5
1 2 3 4 5	Describe how a space that promotes safety, bonding, and bi-directional intercultural learning can be established when working in a group.	1 2 3 4 5
1 2 3 4 5	Understand the importance of listening and doing bi-directional partnership.	1 2 3 4 5
1 2 3 4 5	Identify the guiding principles of Community Based Participatory Research (CBPR).	1 2 3 4 5

Please briefly describe your experience with community-engaged or partnered or participatory research.

Did today’s training meet your expectations? Why or Why not?

How could today’s training support you in doing community-engaged (or partnered, or participatory) research in your community?

Were there any topics that were covered that needed more discussion time?

What additional information could have been provided to aide your understanding of the presented topics?

Thank You

REFERENCES

- Israel, B.A., Eng, E., Schulz, A. J. & Parker, E. Introduction to methods in community-based participatory research for health, 2013. 2nd Edition, San Francisco, Jossey-Bass.
- Holkup, P., Rodehorst, K., Wilhelm, S., Kuntz, S., Weinert, C., Flanders, M.B., Stepan, Salois, E.M., Left Hand Bull, J., Hill, W. Negotiating three worlds: Academia, nursing science, and tribal communities, Journal of Transcultural Nursing, 2009, 20, 164-175
- Jones, A., with Jenkins, K. Rethinking collaboration: Working the Indigene-Colonizer Hyphen, Critical and Indigenous Methodologies, Denzin, Lincoln, Smith (eds), SAGE, 2008, 471-486.
- Tuhiwai Smith, L., Chapter 7, Articulating an Indigenous Research Agenda, in Decolonizing Methodologies, Research and Indigenous Peoples, Zed Books, 1999, 123-141.
- Minkler, M., Wallerstein, N. (editors), Community-Based Participatory Research for Health: From Process to Outcomes, 2nd edition, San Francisco, Jossey-Bass, October 2008.
- Wallerstein, N.B., Duran, B. (2006) Using Community-Based Participatory Research to Address Health Disparities. Health Promotion Practice. Vol. 7, 3, 312-323.
- Walters, K.L., Stately, A., Evans-Campbell, T., Simoni, J.M., Duran, B., et al., (2009). “Indigenist” collaborative research efforts in Native American communities. In A. R. n (Ed.), The field research survival guide. (pp. 3-26). New York, NY: Oxford University Press.