GUIDING PRINCIPLES FOR ENGAGING IN RESEARCH WITH NATIVE AMERICAN COMMUNITIES



### A Collaborative Effort By:

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## Introduction

This document is intended for use by researchers, both non-Native and Native, working with Native American peoples and their respective communities.

In response to past injustices, research to promote individual, family, and community health requires attention to issues of social justice and the distribution of resources. Thus, engaging in research with Native American communities warrants a careful review of principles that can help investigators to be more aware of Native-specific issues (e.g. cultural values, diversity, appropriate protocols and approval processes), and conscientious in their interactions with Native partners throughout the research process. Until recent decades, Native American people have had little or no representation in the research process.

This document was developed by a multi-ethnic group of researchers and community consultants, including individuals who are also active tribal members, to:

- 1) provide written guidance when encountering challenges in research relationships and processes;
- 2) elicit thoughtful discussion among researchers, and;
- 3) increase awareness of our responsibilities as investigators not only to the individuals participating in research but also to the communities.

The reader should note that this document is limited in its ability to convey the amount of time and effort it takes to get to a place of understanding and knowing a community even before the research process begins. Additionally, research in partnership with one Native American community does not necessarily translate to processes or procedures needed in another community, thus highlighting the uniqueness of each tribal nation. We intend for this to be a living document<sup>1</sup> that can be adapted and refined as new approaches to research are developed and as institutions and researchers confront diverse situations.

<sup>&</sup>lt;sup>1</sup> If you have a vignette arising from personal experience that illustrates the importance of one or all of the principles, we request that you submit your vignette to Doreen Bird, MPH at dbird2@salud.unm.edu for inclusion in future versions of this document. Please be sure to include your contact information.



## Definitions

For the purposes of this document, the following definitions are used:

**Culture:** Culture and traditions vary greatly between Native American communities. Native American individuals and communities also vary in adherence to their cultures of origin and to Western cultural values and beliefs. For many Native American people, spirituality and religion are generally perceived as an integral aspect of culture. Spirituality also takes on many forms within Native American communities, from use of traditional Indigenous practices to Christian beliefs.

**Cultural humility**<sup>1</sup>: A commitment and active engagement of continual selfevaluation regarding the interaction and impact of one's culture(s) on a given situation or relationship so as to cultivate mutually beneficial partnerships that recognize and remedy any power imbalances.

**Community:** There is no single definition of community that applies to every situation. This term can be co-defined with partners in the research process. For example, a Native American community could refer to an entire tribe, smaller groups within the tribe, an urban Indian community composed of individuals from different tribes, or the larger Native American community within a city, state, country, or the globe.

**Native American:** A member of any of the Indigenous peoples of the Americas. We recognize that there are a number of other preferred terms. We also recognize that there are native peoples outside of the United States, but for the purposes of this document, we refer to Indigenous peoples of, or residing in, the United States when we use the term Native American.

**Non-Native:** An individual who is not a member of the Indigenous peoples of the Americas. We recognize the diverse histories of researchers of different races. We have selected this general term to increase the applicability of this document to researchers of all races/ethnicities not of Native American descent or heritage. This encourages the reader to consider differences in historical experiences, assumptions and stereotypes.

**Tribal Sovereignty:** "Sovereignty" is the authority of a state or nation to govern itself. Tribal sovereignty in the United States of America provides federally recognized Indigenous tribes the inherent authority for self-governance. However, the federal government recognizes tribes as "domestic, dependent nations," meaning that they have local sovereignty, but not full sovereignty as other nations in the world. Thus, many Native American communities in the USA are, or belong to locally sovereign nations, and thus, have their own governance, laws, and leaders that function independently.

<sup>1</sup> This term was presented at the University of New Mexico Master of Public Health 2011 Community Based Participatory Research Summer Institute, facilitated by Dr. Nina Wallerstein and Dr. Tassy Parker. Dr. Parker discusses "cultural humility" to demonstrate the application of Indigenous knowledge and cultural core value systems in health disparities research. The original article is included in the Resources section.

## **Guiding Principles**

We offer 11 principles to guide research collaborations with Native American communities. These principles are all of equal importance and are presented in no particular order. Within the explanation provided for each principle, we offer illustrative vignettes<sup>2</sup> and questions to elicit discussion. We have also summarized how each of the principles may be utilized throughout the research process in a visual diagram.

### Principle 1: Native Centered

- Native centered means that Native American communities and people are the driving force of the research.
- Native knowledge is at the heart of the research endeavor and Native American people are the leaders and voice. "Nothing about us without us."
- Research activity and action are centered on issues that are central to the Native American community, not the research center, sponsoring institution, or agency. Unite with Native American people to assist in achieving their visions and goals.

### - VIGNETTE -

Researchers invested many hours with a Native American community by attending community programs, going to public events, and connecting with community members in informal ways before they were invited by the leadership of that community to assist with the writing of a grant for research purposes. Members from the community, including family members, youth, service providers, elders, and cultural leaders, participated in the initial planning meetings, as well as subsequent meetings to provide continued guidance. Respecting the knowledge that already existed in the community and listening to what the community wanted allowed the researchers to integrate their ideas into the grant proposal. A community member became the identified Principle Investigator, and other community members were also selected to fill key roles.

- Am I working to achieve my agenda or am I working with the community to assist in visualizing, articulating, and developing their plan of action?
- Is my institution able and/or willing to give this Native American community the time, resources, and expertise needed to meet their expectations?

<sup>&</sup>lt;sup>2</sup> Most of the experiences drawn upon to develop the vignettes are centered in the Southwestern region of the United States. We hope that other research centers can adapt vignettes to incorporate their specific regional/tribal experiences.

### Principle 2: Respect

- Treat all individuals and communities participating in research with respect. Remember, it is an honor to work with Native American peoples in research.
- Purposefully seek understanding of the community and their reasons for collaborating in research. This understanding will guide the researcher in showing regard for the community.
- Respect and honor tribal sovereignty, cultural traditions, and diversity among and within Native American communities.
- Be aware and respectful of existing community protocols. Many communities have specific protocols of who to go to and how to go about garnering approvals for all research activities.



A seasoned researcher attended a meeting in a new community to introduce a project to local residents. One of the community members spoke up and said "We have been researched to death" and "We never see anything come out of the research." The researcher realized the community members may be responding to past injustices of researchers whose work ended up stigmatizing the community. The researcher showed respect by taking the time to listen and validated their concerns by asking "What is it that I can do differently?" One person responded, "Show your respect by spending time in our community, being patient and listening when leaders speak, attending our community events, and advocating for our tribe's voice to be heard. Sit back, listen, and be involved."



- Am I aware of the protocols within a particular Native American community for research projects? Am I aware of the protocols for convening and facilitating meetings? To whom can I go and how else can I learn the protocols (e.g., calling tribal community center to ask for guidance, talking with an elder or youth from the community, knowledgeable colleague familiar with community, etc.)?
- Is the Native American community with whom I am working a sovereign nation? Am I aware of and respecting the government structure, laws, and policies, as well as specific procedures for engaging in research with this community? Am I aware of where the Native community's laws might converge or diverge from the laws and policies of my institution, university, state, etc.?

### Principle 3: Self-Reflection and Cultural Humility

- Be mindful of one's own cultural and class biases and how these biases can affect researcher interactions in Native American communities and the research they undertake.
- Strive to develop self-awareness and have a respectful and humble attitude toward diverse points of view, which are shaped by the individual histories of each community, as well as the distinct traditions that inform these perspectives.
- Engage in research with the understanding that Native American community members have wisdom, knowledge, expertise, and experience that is relevant to their community and to our efforts as investigators.
- An individual cannot master cultural competence for all Native American cultures or tribes. Believing that one has attained "cultural competence" when working with Native American communities can lead to reliance on faulty assumptions and stereotypes, and undermine the research.

### – VIGNETTE ———

A Native American researcher was attending a meeting in her own community. A non-Native community provider introduced her as "a resource from the University." The researcher then handed out program materials and business cards. The community's initial response was, "We are all resources, too!" One community member pushed the researcher's materials aside. The researcher suddenly realized that, although unintentional, the introduction and the institutional authority implied by the materials suggested to community members that the researcher considered herself the expert in this situation. After a lot of thought and consulting with colleagues, the researcher realized the importance of approaching projects with humility and careful self-reflection to ameliorate power imbalances.

- Am I using my position, credentials, or power for this person/community?
- Am I continually mindful and actively reflecting on myself for any assumptions I may be making that influence the way I interact with others and conduct research?
- Am I recognizing the expertise of everyone in the community?

### Principle 4: Authentic Relationships

- Build relationships that are sincere, enduring, and based upon mutual trust and respect. Genuine relationships are the cornerstone of mutually beneficial collaborations and equal partnerships.
- Relationship-based research will emerge and survive through challenges with positive transformations on all sides of the partnership.
- Enter into partnerships with the community and community members with the intention of building and sustaining a long-term commitment to the community.

#### ------ VIGNETTE ------

A local provider was asked to assist a rural Native American community during a crisis situation. He gave the community his full attention and was genuine in his willingness to serve. He engaged with many community members and providers as they dealt with the issues at hand. Once the crisis was over, the community reached out to him to work on other projects that would benefit their tribe. Again, he was genuine and always willing to help. His partnership with the tribal community has grown into developing more proposals and projects. His years working with the tribe have led to authentic partnerships and lasting friendships. Community members often consult with him over the phone, text message him and send him emails when they want him to review something. The tribal members have grown fond of the provider and continue to engage in research projects with him to this day.

- How am I demonstrating that I am fully present with this person/community?
- Am I an active participant in interactions and interpersonal moments that shows my sincerity in assisting the community?
- Am I willing to commit to working through challenges that will inevitably rise, to grow and learn within myself as I get to know the community, and develop relationships that may extend beyond the life of the project.

### Principle 5: Honor Community Time Frames

- Concepts of time differ among various cultures. Tribal community timelines may be influenced by seasonal cycles, traditional events, and governmental functions. As one Native community member phrased it, "spiritual time" is the ultimate clock by which all events take place and goals or projects are accomplished.
- Research culture sometimes creates pressure to "get things done quickly" without consideration for the communities' timeframe. At other times, the research process may move so slowly that Native community members question whether the original purpose of the project will meet community needs in a timely fashion.
- Many Native people value time to process information. This time may be used to reflect on new concepts or translate the concepts into Native thought. Provide time for moments of thoughtful silence.

### – VIGNETTE –

As a researcher was starting the planning process, she asked a local tribal community member what to keep in mind during the yearlong project. The designated community liaison stated that the tribal community had certain events (ceremony, political, funerals, school activities, etc.) throughout the coming year. The liaison recommended the researcher sit down with their local community contact to outline the length of the project and to develop a timeline that encompasses both the research and community events. During this conversation, the community contact also reminded her that the research timeline and the community event timeline had to complement each other in order to be respectful and move the research initiative forward. The researcher made sure to keep her timeline flexible and allow additional time at the end for unexpected community events.



- Is my time frame realistic for the research project in relation to the community's activity level and am I planning accordingly given the different concepts of time?
- What projects or activities occur annually to which my community partners will need to attend?
- Am I taking time to reflect on the information and how it translates into Native thought? Am I giving the community time to translate into their own Native worldview?

### Principle 6: Build on Strengths

- Become aware of the strengths and particular abilities within Native communities; explicitly recognize these aspects and build upon them. Focus on the community's culturally-protective strengths and other assets throughout all stages of research.
- The tone of written research is highly valuable for its ability to positively impact the community by emphasizing resiliency factors and inspiring hope.

#### — VIGNETTE ———

A new researcher was excited to begin a project in a Native American community. He came to the initial meeting with data and statistics from recent Centers for Disease Control and Prevention, Department of Health and Indian Health Services reports. He brought up concerns regarding the high rates of alcohol use, depression, diabetes, and adverse childhood events among this population. He began by asking the community partners to give their opinions and examples of why and how these statistics are played out in their community. After the initial meeting was over, the community partners were left with feelings of negativity and hopelessness. They were not sure that they wanted to continue working with this particular researcher because he pointed out all the bad things going on in their community. This might have been avoided if the researcher balanced out his meeting by bringing forth some positive qualities inherent in this community.

- Am I actively searching for positive qualities or strengths in the community?
- Am I coming from a positive or negative framework in how I perceive the community?

### Principle 7: Co-Learning and Ownership

- Co-learning involves a reciprocal exchange of knowledge and ideas. Tribal community partners bring their expertise across multiple areas, including a deep understanding of their communities' traditions, values, methods, and knowledge. Researchers bring expertise in academic research methods and processes.
- Build community capacity. Consider what the Native American community would like to learn and benefit from the researchers just as the researcher gains important knowledge from community members.
- Acknowledge that everyone has important contributions to make in research. Community input is vital to fostering ownership and sustainability of the positive project outcomes.
- Native communities have the right to ownership and control over their own data and may choose to share or not choose to share ownership of the data.

#### – VIGNETTE —

In one collaboration between a Native community and a research center, community members determined the degree to which their culture and traditions would be included in the project. Both community members and researchers took different sections of the grant to write, with all contributing equally to the final product. Research partners provided technical assistance whenever needed during the grant writing process, facilitating the community's capacity to write grants on their own in the future. The community gained approval for the project by consulting with the elders and tribal leaders. The researchers learned the approval process through the institutional IRB. This process helped build capacity for the community and for the researchers. It also instilled a sense of pride and ownership that carried the project forward even after funding ended.

### Questions To Facilitate Putting Principle Into Practice:

- How am I helping to build capacity in the community through the research process (e.g., using research funds for equipment retained by the community, hiring community members, bringing tribal representatives to the research center, providing trainings, etc.) and what am I learning from the community that increases my own skills and capacity?
- Am I providing community members opportunities to contribute their knowledge in meaningful ways? Am I prioritizing the use of existing programs and resources in the community?
- In what ways am I encouraging community members to take ownership of the project to ensure sustainability?

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### Principle 8: Continual Dialogue

- Ensure that communication about research is *understandable*, *relevant and accessible* to the members of the community involved.
- Communication flows both ways. A continual and open dialogue may facilitate co-learning, prevent misunderstandings, and address concerns before they become problems.
- Be proactive in finding out the appropriate people and programs needed for ongoing communication within each community and research project.
- Provide findings back to community stakeholders on an on-going basis.

A researcher came before the tribal council:

*Council* – When was the last time you provided council with an update on this project?

– VIGNETTE –

*Researcher* – I have not provided an update to council since the project was approved by the Institutional Review Board two years ago last spring. I didn't know I was required to.

The council's questioning caused the researcher to reflect on her own expectations for communication. She realized she needed to put more effort in aligning with the community's protocol for how information flows to and from the community/ researcher, in order for local decision-making to occur and project goals/ requirements to be met.

- Am I actively listening? Am I choosing not to talk in order to give community members a chance to speak?
- Am I intentionally creating a relationship and atmosphere that allows my partners to feel comfortable enough to bring up issues of concern?
- Am I communicating with the proper stakeholders of this community? Is there a health board, tribal IRB, health director, tribal council or traditional leader with whom I should be in contact? Am I updating the right people at the right time?

### Principle 9: Transparency and Accountability

- Be open and clear about all activities and information throughout the research process in order to build trust which may have been compromised by past negative research endeavors in the community.
- Take responsibility for all actions and consequences of those actions when engaging in research with communities.

#### – VIGNETTE ———

A tribal leader came across information regarding her community while surfing the web and was concerned at the way her community was portrayed. When asked about this information, the researcher, who had posted the information, stated that he had assumed the proper approvals had already been obtained and it was not his fault that the information was put on the web. The researcher was caught off-guard by the community member. He did not reveal that, despite being made aware of the need to update tribal administration about new actions related to the research project, he still neglected to inform them this information was being placed on the web for fear that it would cause more discussion and delays than were necessary for such a small detail. Although the information on the website of itself was not a huge concern to the community and would have easily been approved if taken through the appropriate protocols, the community lost some trust with this researcher for not being open and for not taking the responsibility of remedying the situation.

### Questions To Facilitate Putting Principle Into Practice:

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- Have I clearly defined what my position as a researcher entails? Have I clearly defined what my institution can and cannot provide? Should these expectations be in writing?
- Am I being open about and taking responsibility for all research activities?
- Do we have a mutual understanding of each other's expectations?
- Do I know whose approval is needed for different aspects of my project? Do I know whom to work with in the community regarding consents, permissions, etc.?

### Principle 10: Integrity

- Act with honesty and morality throughout every phase of research.
- Adhere to the existing ethical guidelines that are developed for and by Native peoples and communities in addition to general ethical guidelines for researchers.
- Be vigilant about protecting Native American communities, as well as individuals, from harm.
- Work to preserve and strengthen the wholeness of Native peoples and communities.
- Understand that the community's rights take precedence over the researcher's pursuit of knowledge and personal career development. The community and any member of the community has the right to say no to any part of or the entire research project.



A tribal council required a researcher to make several changes to his submitted presentation before they would give approval for the researcher to present at an upcoming conference. One request required the researcher to delete a major finding from his presentation. After much discussion, the researcher asked if there was any way that the information could be presented in a more acceptable manner in order to keep this central finding in the presentation. Ultimately, the researcher took out this finding from the presentation. This researcher struggled with which guidelines to adhere in order to maintain the integrity of his work, and decided that the reasons for which this Native community had asked him to take out his findings held greater justice for this community than would be demonstrated in presenting the findings.



- How am I showing my integrity? What are the code of ethics to which I refer in guiding my actions and decisions to ensure the morality of my research?
- Where is all the private/confidential documentation being kept? How will all the private/confidential documentation be handed back to the community or destroyed at the end? If destroyed, how will this be documented?

### Principle 11: Community Relevance

- Be mindful that historical experiences directly relate to Native communities' present situations and impact the relevance of any research project.
- Develop research projects that have meaning and purpose within the Native community's way of being and knowing.
- Ensure that research findings are useful and accessible to participating communities by providing information that contributes to tribal-specific solutions, greater well-being, and positive policy impact.

#### ------ VIGNETTE -------

A researcher came before tribal leadership to present an HIV prevention project that she wanted to begin at a school-based clinic on the reservation. She presented information that supported counseling and testing as an HIV prevention strategy. Leadership was skeptical of the need for such an intervention and questioned whether it was the most productive use of the clinic's limited resources. Leadership said that the wellbeing of their youth was of utmost importance and they were open to other project ideas that may better meet concerns such as substance abuse and teen pregnancy, but they did not endorse the proposed project since HIV prevention was not a priority. During the discussion of the project, members of council expressed concern about the loss of their tribal language and the limited number of youth in the community learning to speak the language. The researcher still hoped to offer her expertise in children's behavioral health, but also realized her previous proposal did not take into account the community's present concerns. Incorporating what she had learned, a few months later the researcher presented a different project. This time the project was a comprehensive substance abuse and risky sexual behavior prevention project that focused on strengthening cultural identity. A major component of the intervention was language preservation. Tribal leadership endorsed the project and devoted tribal resources to support the program.

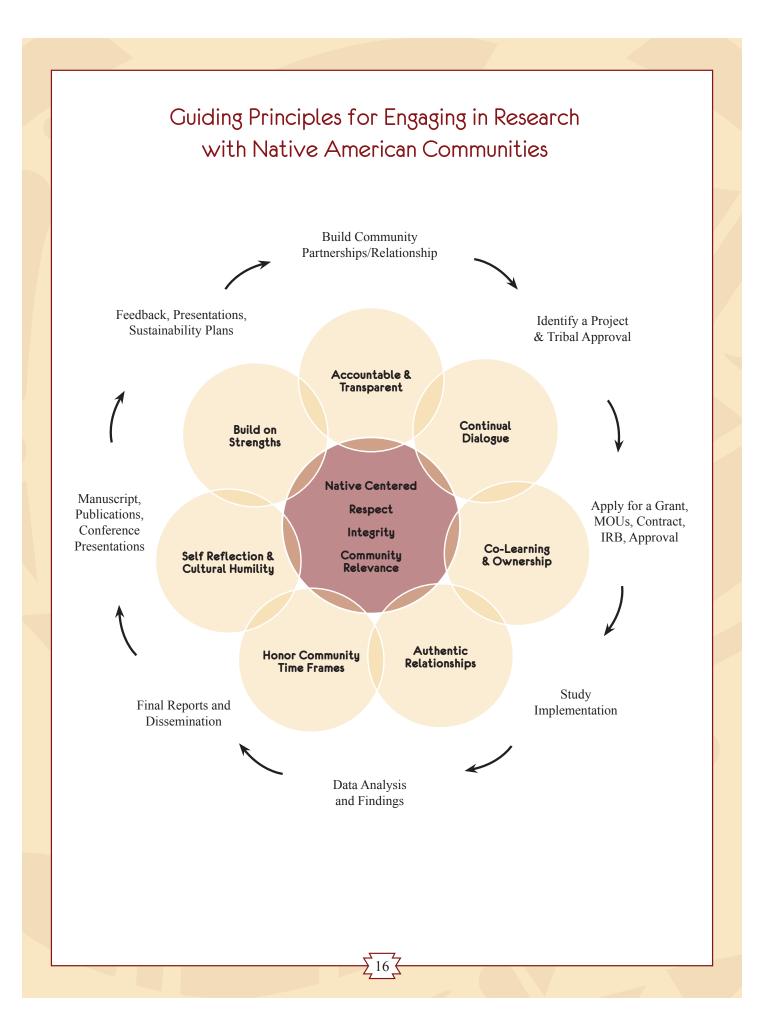
### Questions To Facilitate Putting Principle Into Practice:

• How is this research going to help the community and/or individuals in addressing the community's identified priorities (e.g., treatment/intervention, prevention, jobs, training, and equipment)?

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- Rather than going into the community and leaving once my research project is complete, am I willing to follow up with research findings that reveal barriers, inequalities or other issues negatively impacting the community by providing culturally relevant recommendations and engaging in socially responsive action at a systemic level?
- How am I changing policies/behavior/norms in my current institution and the way I engage in research with Native American communities, now that I know the history of disrespect/abuse?

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### Resources

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#### **Trainings and Presentation**

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**Suggested Citation:** Straits, K.J.E., Bird, D.M., Tsinajinnie, E., Espinoza, J., Goodkind, J., Spencer, O., Tafoya, N., Willging, C. & the Guiding Principles Workgroup (2012). Guiding Principles for Engaging in Research with Native American Communities, Version 1. UNM Center for Rural and Community Behavioral Health & Albuquerque Area Southwest Tribal Epidemiology Center.



# Special Thanks

We want to extend a special thanks to our partnering Native American communities and our more experienced Native researchers who have been willing to teach us and help us learn from our mistakes. They have also enriched our work by opening their communities to us, and by sharing their strengths and knowledge. Without their collaboration in these research endeavors, we would not have been able to develop the principles and vignettes we offer for other researchers. It is our hope that you continue the progression towards social justice and having healthy, thriving tribal communities.

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## Acknowledgments

Steven Adelsheim, MD; Deborah Altschul, PhD; Utahna Belone (Navajo/Zuni/Oglala Sioux); Robert Butler, MS; Roberto Chené, MA; Melanie Domenech Rodríguez, PhD; Cheryl Drapeau (Zia); Kevin English, RPh, MPH; Francine Gachupin (Jemez), PhD, MPH; Brian Isakson, PhD; Marianna Kennedy, MPA, MSW, MPH; Lindsay Lennertz, PsyD; Tassy Parker (Seneca), PhD; Michelle Suina (Cochiti); Greg Tafoya (Santa Clara), MPH; Esther Tenorio (San Felipe); Nina Wallerstein, DrPH; and the New Mexico Center for the Advancement of Research, Engagement, & Science on Health Disparities; and the many others from our institutions, research centers, and Native American communities.