Toward a Pueblo Methodology: Pueblo Leaders Define and Discuss Research in Pueblo Communities

by

Doreen M. Bird

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Graduate Supervisory Committee:

Bryan McKinley Jones Brayboy, Co-Chair
Mary Margaret Fonow, Co-Chair
K. Tsianina Lomawaima

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ABSTRACT

The history of research in Indigenous populations is deeply problematic. Power imbalances have led Non-Indigenous researchers and outside institutions to enter Indigenous communities with their own research agendas and without prior consultation with the people and communities being researched. As a consequence, Indigenous scholars are moving to take control and reclaim ownership of the research that occurs in our communities. This study, conducted by a Pueblo researcher with Pueblo leaders, investigates their definitions of and perspectives on research. Eleven semi-formal interviews were conducted in 2017 with a subset of tribal leaders from the 19 Pueblos of New Mexico. Results show that Pueblo leaders define research using action words such as compiling, gathering, or looking for information to determine a cause or to find out more about a situation. Leaders state that research is "inherent to our beings" and gave examples such as "singing to plants," "knowing when to plant and hunt" and sustaining our cultural ways as Pueblo activities considered research.

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INTRODUCTION

The main objective of this study is to gain a foundational understanding of how Pueblo leaders define research in their own terms and gain knowledge about the current perceptions and priorities of research to inform the development of research policies and guidelines for Pueblo communities. The central research question is, "How do Pueblo leaders define and discuss research in Pueblo communities? The reclamation of research by Pueblo scholars could result in a gift to Western academic science. This dissertation is broken up into three parts; 1) a journal article, 2) a book chapter, and 3) a policy paper. The researchers' positionality and past experiences with research in American Indian and Alaska Native communities drive this inquiry to address the injustices that have occurred in research with Indigenous populations. The journal article highlights a literature review, methodology and results of the current study. The book chapter highlights Pueblo constructs that align with scientific research guidelines for human subjects' protections and the application of these constructs to Western science. And finally, the policy paper addresses the need to establish research guidelines for the protections of Pueblo people and their communities along with recommendations for the Pueblo leaders and their communities.

PART 1:

Toward a Pueblo Methodology: Pueblo Leaders Define and Discuss Research

The purpose of this study is to gain an understanding of tribal leader perspectives on research in Pueblo communities. Much of what has been written in the scientific literature about the history of research in American Indian and Alaska Native (AI/AN) communities has discussed issues of power imbalances, negative stigmatization of AI/AN communities, and a feeling of mistrust in the research process (Smith, 1999). Yet, there is a lack of information in the literature specific to Pueblo communities and their tribal leaders' perceptions of research occurring in their communities. Information gathered through this study will inform future development of guidelines and policies that Pueblo communities can use when engaging in research.

The negative history of research on Indigenous populations has left behind a feeling of mistrust among Indigenous populations (Christopher, Watts, McCormick, & Young, 2008; Lambert, 2014; Sterling, 2011; Trimble, 1998; Wallerstein & Duran, 2006). Many Indigenous communities and community members feel "we've been researched to death" (Smith, 1999). This study highlights main debates in the history of research with American Indian and Alaska Native (AI/AN) populations and speaks back to the power imbalances between the researcher and the researched. The author's statement of positionality is followed by an overview of relevant history informing this work. Next, an overview of the main debates that have emerged within the history of research with AI/AN populations will be discussed including the stigmatization of minority populations

based on research findings. This leads to the central research question of this project: If we have been "*researched to death,"* then why do our Pueblo communities do so much research? Recommendations include strategies to increase cultural sensitivity and respectful engagement in research with Pueblo, AI/AN and other Indigenous populations.

Kewameh Auw Sutha: Kewa is Where I Come From

Through my lineage, upbringing, and continued engagement as a Pueblo woman I bring a distinctive and valuable perspective to research. The roots of my knowledge come from growing up in Santo Domingo Pueblo with my grandparents and extended family participating in community life on our tribal lands. Pueblo societies have endured colonization by Spanish conquistadores and the United States government. We continue to thrive and maintain traditional ways of being in relation to the world and one another. I am fortunate to speak my traditional language fluently and to have been raised by a family deeply rooted in prayer and spirituality. I maintain a deep-rooted connection to my ancestors, my people, and my community. I have been privileged to gain a Western education and have engaged in Western academic research with other tribal communities while maintaining connection to my community of origin. As Indigenous researchers, we are in a key position to influence a paradigm shift in the way scientific research is conducted in our communities. This research project, conducted by a Pueblo woman scholar, highlights the need for culturally relevant and respectful research engagement with all Indigenous and Pueblo populations.

The fact that I am a Pueblo researcher doing academic research with Pueblo people is an innovative and important step in speaking back to the past injustices of being researched on by outsiders and non-natives without significant investment in or

commitment to our communities. I grew up in Santo Domingo Pueblo and have been raised on the values of love and respect for my community. I am embarking on this research to have a positive impact and real time applicability in our Pueblo communities. I hope that this research can stand as a culturally sensitive and respectful model that can be replicated by other Indigenous scholars.

History of Research with AI/AN Populations

The literature on American Indian and Alaska Native populations is vast and varied. The settler colonists' documentation of the first people of this land is traceable back to first contact with Columbus in 1492 (Pevar, 2012). Historical documents record observations of American Indians as savages, unable to care for themselves (Lomawaima & McCarty, 2006; Trimble, 1998; Wolfe, 2006). After the first explorers, subsequent colonial governments, including the United States, were interested in information about the Native Americans and the lands they occupied. Currently, the US government is still interested in collecting data about AI/AN populations, as is evidenced by the data requirements of programs such as the National Institutes of Health, Substance Abuse and Mental Health Services Administration, and the Indian Health Services Request for Proposal requirements. Historical scholarship very frequently focused on pathologies and deficiencies of Native Americans in comparison to Europeans/Americans, especially when it came to socioeconomic and health statistics. Reviewing the types of data that the U.S. government has collected in the past helps us gain a better understanding of current opinions, understandings, and priorities in research on Indigenous populations.

The history of research with Native Americans is tainted with negative examples such as the stigmatization of villagers in Barrow, Alaska through the perpetuation of the "drunken Indian" stereotype (Foulks, 1989) to the more recent re-use of Havasupai blood samples for research purposes the participants never originally consented to (Sterling, 2011). Research findings have perpetuated negative stereotypes related to poverty, chronic disease, mental health, and substance abuse.

U.S. Policy Supports AI/AN Research

Settler colonial societies such as the Europeans who came to settle the Americas have been obsessed with documenting everything possible about Native Americans to create a discourse of dominion over the nation's first inhabitants and their lands. Wolfe (2006), describes how making the distinction between dominion and occupancy of the land highlight the settler colonial project's reliance on eliminating Native societies. Documentation was able to prove hunter gathering societies as pragmatic users of the land versus static use of the land such as agrarian societies. The United States government followed suit by documenting population numbers, educational achievement, religious affiliation, land base, and many other variables such as diet and brain size (Lomawaima and McCarty 2006; Pevar, 2012; Weaver 2016). Green and Troutman (2002) share stories of Native American students as they endured the boarding school system. Detailed documentation of students included basic demographic information such as name, age, height, and weight; in addition, however, the extreme surveillances of the school also recorded demeanor, academic profile, conduct, religion – even the names of their Sunday school teachers (Green and Troutman, 2000;

Lomawaima, 1994). This is one example of the early documentation and statistical evaluation efforts of American Indians in this country. It is important to note that the research subjects often did not consent for their information to be collected.

An example of a 20th century U.S. serious data collection effort in the American Indian population was the 1927 survey undertaken by the Institute for Government Research (IGR). The IGR's final report, *The Problem of Indian Administration* (Meriam, et al., 1928) requested by the Secretary of the Interior, presents detailed information on the status of Indians in the U.S. The Survey Team was charged to gather detailed information on many tribal communities, to assess the land base and status of the Indians, and to evaluate whether the Office of Indian Affairs was fulfilling its responsibilities. The Meriam Report is a prime example of how much research done *on* Native Americans without their prior knowledge, consent, or control. The paternalistic U.S. government contracted with a research organization to collect data and report back on many variables such as household information, land ownership, education, and poverty levels, even the types of food in their diets. This fascination with the surveillance, documentation, and descriptions of AI/AN populations has not ended, but continues today, including studies of mental health, substance use, and genetic research (Dickerson and Johnson, 2012; Malhotra et al. 2014). Because much of the current research being conducted in AI/AN populations is tied to federal funding streams, reporting requirements continue to push for the collection of numbers from activity logs, meeting sign-in sheets, numbers screened, dollars spent, and so on. We can see that many current federally funded programs continue the systematic data collection efforts that started years ago.

Health Research in AI/AN Populations

One of the well-documented examples of the mistreatment of American Indians occurred in the 1970s when physicians in the Indian Health Service (I.H.S.) performed forced, involuntary sterilizations of hundreds of American Indian women and girls (Moss, 2016). The women's right to bear children was unknowingly taken away due to the lack of basic respect for Native American women during those times. This negative treatment of American Indians in the United States healthcare system correlates to the mistreatment of African American minorities in the often-cited Tuskegee Syphilis Experiment, when Black men in the South were withheld penicillin, a treatment for syphilis, to study the natural progression of the sexually transmitted disease (Jones, 1981). Although the Tuskegee experiment started the discussion of ethics in research, many more examples of unethical practices in research followed.

There has been a continuous flow of health research in American Indian and Alaska Native populations. The Alcohol Studies in Barrow, Alaska provides one historical example of the stigmatization of an entire community because of the way the data was interpreted and reported (Foulks, 1989). The negative stigmatization of the *drunken Alaska Native* devastated and angered local Alaska Natives and continued to add to the negative stereotyping of AI/AN's in the larger U.S. society. On January 22, 1980, a New York Times press release headlined "Alcohol Plagues Eskimos;" on the same day, The United Press International Wire Service wrote its story under the headline, "Sudden Wealth Sparks Epidemic of Alcoholism," with the subhead, "What We Have Here is a Society of Alcoholics" (Foulks, 1989, p. 13). The community was not consulted before the data was released. What the researchers failed to report was that the data was taken

from a small sample of the population, and most of the population were non-drinkers. These examples from the history of research engagement with AI/AN populations create a critical view of past research and highlight the injustices that need to be addressed including the need for a focus on strength-based studies.

Main Debates in AI/AN Research

Although Non-Native allies have come a long way by beginning to introduce culturally sensitive and community-driven research to the academy (Belone, et al 2016; Goodkind, et al., 2015; Whitbeck, Adams, Hoyt & Chen, 2004), the five following major themes have emerged as issues needing attention according to the literature on research with AI/AN populations.

1. *Mistrust in research*

A deep-rooted level of mistrust of academic research still exists today in many Native communities. In the case of the study on diabetes among Havasupai Indians in Arizona in 1989, researchers were found to have violated ethics codes on several counts, including lack of informed consent and violation of civil rights (Mello & Wolf, 2010; Sterling, 2011,). Researchers sparked Native mistrust when they used blood samples intended for one purpose for another; and shared those same blood samples with other researchers to use in genetic studies (Pacheco et al 2013; Garrison and Cho, 2013; Sterling, 2011). As a result of the subsequent lawsuit *Havasupai Tribe vs. Arizona Board of Regents*, ASU paid out settlements to 40 of the 100 research participants. Since then, stricter protections and enforcement of existing protections were put in place at the University. All future research with American Indian participants requires an in-depth cultural review process

before research is approved. The unfortunate outcomes of this study remind American Indian communities of the real potential of harm when engaging in research with outside entities and institutions.

2. *Research without local benefit*

Another debate in the history of research with AI/AN communities is that research done in American Indian and Alaska Native communities has done more to benefit science and academic knowledge than it has benefitted the communities where the research took place (NCAI, 2012). Even within my own Pueblo community, that question always comes up, "Who's going to benefit from the research?" The Navajo Nation Institutional Review Board (IRB) has been guiding researchers to ask questions that can produce results that would benefit the people of their Nation.

Recent conversations among Indigenous scholars address how western research approaches and practices have continued to perpetuate the colonizing mindset in Western academic institutions (Straits, Bird, Tsinajinnie, Espinosa, Goodkind, et al, 2012). An academic researcher who considers him/herself the "expert" when coming into AI/AN communities is a common example of a colonial mindset in research. Indigenous scholars express the need to re-claim Indigenous practices and incorporate them into the way research is conducted with our Indigenous communities (Lambert, 2014). Pueblo scholar Michelle Suina, PhD moves forward the discussion of data sovereignty by talking about the hard issues such as tribal ownership of all data including the right to review and approve publications and data dissemination (Suina, 2017). Some tribes are asserting their right to approve research projects that will benefit the overall community, unlike in

the past when much of the research was done to benefit the academic researchers and institutions without benefit to the local community (Lomawaima, 2000; Smith, 1999).

3. Decolonizing methodologies

Māori scholar Linda Tuhiwai Smith was instrumental in expanding the realm of Indigenous research with the publication of her groundbreaking book *Decolonizing Methodologies* (Smith, 1999). Dr. Smith's idea of shedding research practices that were not congruent to the values of the Maori people set the stage for other Indigenous researchers to venture out into the research arena by creating methodologies that were congruent with local values and useful for Indigenous communities. Smith's critique of the Western academic system of research has paved a way for many current Native American researchers who have navigated the ranks of academia by engaging in research that pushes colonial boundaries while maintaining scientific rigor through standard, quantitative, and qualitative scientific methods. During an exchange in 2016 hosted at Arizona State University among Māori, Pueblo, Diné, and Kanaka maoli/Native Hawaiian doctoral students, Dr. Smith talked about her early years in research, searching but failing to find books on the shelves about Indigenous research. She related that she wanted to write a book that would stand apart from the other research books that were on the shelves of any bookstore or library. She wanted to address years of colonial paternalism and power imbalances, struggling with oppressive laws and policies designed to wipe out the cultural essence at the heart of being Maori. Hawaiian relatives shared Similar experiences were with whose effects of colonization by England and the United States have left them necessarily embarking on Indigenous reclamation practices in areas such as language revitalization, education of Hawaiian children and families and

indigenous research and scholarship (Goodyear-Ka'opua, 2013; Oliveira & Wright, 2016).

Recent research in the Southwest moves toward incorporation of Native voice in research endeavors (Belone, et al. 2016). Bringing in the Native voice can be done through many avenues such as having community advisory committees involved in local research and making sure there is continual dialogue among the researchers and tribal leadership.

4. *Research on versus research with*

Although there are examples of allies working in a good way with AI/AN communities such as McCarty (Lomawaima & McCarty, 2006) and Wallerstein and Duran (2006), much of the research conducted in Native American communities has been done by outside researchers coming in to the community to extract data and eventually leave the community, often not to be heard from again. Researching *on* a sample of participants has a different undertone from researching *with* that same group of participants. Wallerstein and Duran (2006) describe Community Based Participatory Research (CBPR) as "a transformative research paradigm that bridges the gap between science and practice through community engagement and social action to achieve health equity" (p. S40). Current literature on research with American Indian populations has turned from a conversation of research *on* communities, to research *with* the communities. The CBPR approach has been successfully implemented in Pueblo communities of New Mexico with on-going, long-term research occurring among university/tribal collaborations. Nina Wallerstein and Lorenda Belone's current work with Jemez Pueblo incorporates the Native language in health and language promotion

and prevention activities which helps to gain community buy-in. Dr. Nina Wallerstein has a long-standing commitment to working with the community members in making the research their own and creating a sense of ownership and creativity with the research making it more personal for the local community (N. Wallerstein, Personal Communications, April 27, 2011). The long-term commitment shows the community members that the researchers are invested into creating actionable change based on study outcomes. This speaks back to the literature and community members that state outside researchers come into communities without giving anything back.

Incorporating community knowledge and participation can increase research engagement from multiple generations and sectors in a Pueblo community.

5. Who owns the data?

Data sovereignty is a topic of much debate lately in tribal leader forums as well as in Indigenous research circles (citations, NCAI). Since American Indian tribes have a unique relationship with the United States government because of their inherent sovereignty, acknowledged through treaties and long standing congressional agreements, it is important to acknowledge sovereignty in the ownership of tribal research data. As more tribes reclaim their research activities by creating Institutional Review Boards, research policies, and guidelines (Lomawaima, 2000), it is imperative that Indigenous researchers develop quality data sharing agreements that not only benefit the tribe in research relationships but also acknowledge tribal sovereignty in all aspects of the research process including data ownership.

Often when research comes out of western academic institutions there is great importance placed on producing knowledge that can be shared in scientific journal

publications. Although the scientific method is the golden standard of peer review in place, there is not much emphasis placed on ensuring that all data being presented has been approved for dissemination by the Indigenous communities from which the data come. As researchers, we must include continual dialogue with tribal leaders in our methods to ensure respectful engagement and elicit feedback during the research process. This can be done through quarterly updates to tribal leadership on research activities while incorporating feedback and ensuring cultural values are also being respected.

Pueblo Core Values Can Inform Federal Research Guidelines

Core values such as having respect and caring for all beings have informed Pueblo ways of being for centuries. One way to show similarities in the research experience between Western and scientific research is by highlighting core values that are practiced in Pueblo community's and comparing them to items in The Belmont Report of 1979. Terms found in the Belmont Report such as respect and beneficence can open the door to the discussion of whether they align with Pueblo core values. The Belmont Report, written by the National Commission for the Protection of Human Services of Biomedical and Behavioral Research came out of the need for regulation of unethical behaviors in research because of violations during the Tuskegee Syphilis Experiments. With the adoption of the ethical research guidelines stated in the report, biomedical and social science researchers are all expected to abide by these principles. The following core principles are discussed to highlight points of entry in discussions of research ethics in a context of Pueblo communities.

Respect

A Pueblo-centric definition of respect includes common notions of respect such as having a positive regard for a person, animal or Nature with an added spiritual element such as having reverence for Ancestors. Pueblo Peoples add a deeper meaning to to respecting a person because they also have regard and hold in high esteem the spiritual being and or soul that the person holds with them. The first core ethical principle in the Belmont report is *Respect for Persons.* Respect is a priority in human subject's protections and is also a priority in Pueblo communities. The *Guiding Principles for Engaging in Research with Native American Communities* (Straits, Bird, Tsinajinnie, Espinosa, Goodkind, et al, 2012) stresses the importance of respect in building relationships with AI/AN research partners. In the past, researchers were not always invested in the communities that they collected their data from because of the notion of remaining objective. Many researchers end engagement with the community after the research has ended without making an effort to ensure that the research results can add to the knowledge base to the community and be used to benefit the research participants and community.

Beneficence

The concepts of *Beneficence* and *"do no harm"* are also ethical principles that align with Pueblo values of compassion and caring for one another. I grew up with my grandparents always teaching us to love one another and to take care of one another. Pueblo worldview stresses that our prayers are meant for the whole world. When we pray for the safety and well-being of our people, we also pray for the blessings for the entire world. We are taught to be careful what we say or do, because unintended consequences

produced by our behaviors and our actions might hurt someone unintentionally. I think the value of caring for each other relates to the concept of beneficence and by making sure our words and actions do not harm anyone but also, that our words and actions in research will be of benefit to the people being studied. The value of caring translates beautifully into research ethics and moral guidelines that are carried out by researchers through the types of research they conduct and the approaches they take while implementing a study.

Justice

As Indigenous researchers, we must consider the impact of our research on our relatives when conducting research in our own communities, and on our global relatives of all Indigenous peoples of the world. Incorporating levels of protections for individuals, communities and populations allows for social justice in research as we move the next research paradigm forward. We can all learn and grow from past injustices and treat all persons engaged in the research process with respect for their unique contribution and engagement into the research process. Having the ability to study any Indigenous community is an honor, and it is a special honor to study one's own Pueblo community. All three elements of the Belmont Report including respect, beneficence, and justice, align with Pueblo core values that can increase the cultural sensitivity and relevance to research conducted in their communities. Because it is always easier to highlight the differences between western, academic cultures and AI/AN communities, it is a unique opportunity to be able to highlight these similarities as a Pueblo researcher.

Problem Statement

The history of research with Native American and other Indigenous populations has left a feeling of mistrust among these populations (Trimble, 1998; Christopher, Watts, McCormick, & Young, 2008; Wallerstein & Duran, 2006; Sterling, 2011; Lambert, 2014). When any researcher gathers and has access to tribal specific data, clear guidelines are needed to guide in culturally appropriate ways to engage with our community, data ownership and storage, as well as dissemination of study results. Because of the history of bad research spoken of above, and levels of mistrust lingering, researchers and communities should consider the sensitive issues that need to be addressed when either an outsider comes into the community to do research and even when community researchers are doing work in their own or other Native communities.

The power dynamic between academic researchers and the participants they study has been noted in the past (Lomawaima, 2000) but is rarely spoken about perhaps because of its social sensitivities. Jones and Jenkins (2008) write about their unique experiences doing research as they call it, "Working the Indigene-Colonizer Hyphen." Their poignant title sums up the unique relationship among research partners coming from either the indigenous or the colonizer's backgrounds and in some situations, from both. There is a power dynamic in the way research is currently conducted with indigenous populations. The privilege that cloaks academia affords non-Native researchers the ability to conduct research in minority populations with many assumptions and unspoken authority.

Real world examples of the "*Indigene-Colonizer*" model occurs currently in research projects within many Pueblo communities. For example, a state public health institution and a university in the Eastern United States collaborated with some individuals to undertake a Health Impact Assessments (HIA) in my tribal community. I signed up to be on their advisory committee so that I could be informed of project activities and to be a resource to the study team. The initial reports and data summaries I have received for review left me with the validation that it is *extremely* important for us as indigenous researchers to educate our academic collaborators about our cultural customs and nuances related to relationship building which can ultimately lead to good science. I observed that the academic partners and student researchers involved with the project were not educated on the cultural nuances around collecting, storing, and sharing of data.

One comment I made to the university researcher, regarding my review of their Health Impact Assessment reports included, "We don't even write these things about ourselves with our own data and you all come in here and have no problem writing about us and what percentage of our people have this disease or that illness or mold in their house." Although the outside researchers meant well, it became apparent that proper lines of approvals and communication with tribal leaders was lacking. The cultural differences as well as value differences are important to highlight in the data interpretation process.

Another comment I gave was on a logic model developed by the university students working on the project from afar:

> "The recommendation that was made that increasing housing would lead to reduced overcrowding conditions in the homes, thus leading to an

> increase in positive mental health status among the community members does not make sense to me, because I wonder what will happen to our traditional extended family structures when more homes are built? What happens to grandma who may end up living alone because all her children and grandchildren are moving out? What happens to the language of those children when they do not hear grandma speaking to them in their Native language daily anymore? And what will actually happen to the mental health status of the grandmother when she can't hear the pitter patter of little feet anymore because her family has all moved to the new housing developments?*"* (Author's personal communications with HIA researcher, March 2016)

These are just a few of the challenges that have motivated me to create a study that will inform development of Pueblo research guidelines and policies. Having research guidelines in writing will help tribes regulate research while having guidance for researchers in ways to be culturally sensitive and respectful when engaging in research with Pueblo communities. Development of such policies and guidelines, and training researchers working with Pueblo communities, has the potential to increase the cultural sensitivity, relevance, and quality of the science while promoting mutually respectful relationships among the researcher and the researched.

Significance of this study

Recent real-life experiences that I have had such as seeing university collaborators sharing data about my tribe without involving me or asking me any questions made me leery about what they were meeting about behind closed doors. The real issue later came out that the months of data gathering involving my tribe was being done without former consultation with tribal leadership. This is troubling because the research occurred without express written permissions or approvals from our tribal Governor or tribal council. This has led me to attempt to remedy this problem by getting our Pueblo leaders involved in a conversation about research with the hopes that the information from this study will be used to inform future research policies and guidelines for Pueblo communities. Many of the past as well as current practices in research conducted with American Indian populations have not involved the communities being researched in any of the major decision-making processes that are usually conducted at the outset of a research project. It is time for tribal nations to take control of the research conducted in their communities by establishing strict guidelines and procedures for all researcher~~s~~ to follow when requesting to enter the tribal community for the purposes of conducting research or gathering data. Projects proposed with tribal communities and American Indian populations often are for purposes that are for the sake of research institution and gaining scientific knowledge with little accountability or benefit to the people who may be involved.

Theoretical Framework

The biggest driver of my actions as a Native American researcher are the deep roots of my community, family and cultural values. Any important endeavor we undertake as Pueblo people requires a foundation of connection to spirit; this usually begins with prayer. As a Pueblo woman in academia, I have a unique perspective on implementing, interpreting and translating data from the social sciences. Coming from an epistemological background that is seated in Pueblo spirituality, I have chosen Indigenous Standpoint Theory (Foley, 2003), Tribal Critical Race Theory (Brayboy, 2005), and Community Based Participatory Research approaches (Minkler and Wallerstein, 2008) to guide this research. Standpoint Theory emphasizes the researcher's experiences and perspectives, and thus can help explain the reasons behind selecting certain methodologies and approaches.

I am an enrolled member of Santo Domingo Pueblo, one of the 19 Pueblos of New Mexico, am fluent in my Native language and am engaged in the social fabric of the community. My heritage and years of academic and community research experience affords the researcher a unique perspective on research occurring in Pueblo communities.

Tribal Critical Race Theory (Brayboy, 2005), is important because of its relatability to the Indigenous researcher experience. The social climate in the United States continues to threaten the sovereignty of Native nations. The federal government often chooses which treaties to honor, or not. Tribal CRIT acknowledges that Indigenous researchers of this country take ownership of the research occurring in our communities. Brayboy's Tribal CRIT posits that cultural and academic learning can "complement each other in powerful ways" (p.435), I agree. I believe there is a way to incorporate land,

language and Indigenous knowledges including spirituality into a culturally tailored research and educational system made specifically for indigenous populations that would benefit them for generations to come. The nine tenets of Tribal Crit (p. 429) can be a useful tool in educating researchers and Tribal Leaders in the histories and context in which the research occurs. Once we get more researchers that look like Us, think like Us and will stand up for Us, we will begin the journey of self-education in Pueblo communities of all the wonders of research.

Lastly, there is an approach to research that incorporates notions of social equity and is operationalized through a research approach called Community-Based Participatory Research, also known as CBPR (Chavez, Duran, Baker, Avila, & Wallerstein, 2008). CBPR is an approach to research that can help to eliminate some of the inequities that arise from the research process. In the past, there has been this notion of the researcher as being the expert. Through using the CBPR approach, indigenous communities and community members can have an equal contribution in the research conceptualization, design, analysis, and dissemination processes (LaVeaux & Christopher, 2009; Mariella, Brown, Carter, & Verri, 2009; Novins, Freeman, Jumper Thurman, Iron Cloud Two Dogs, Allen, LeMaster & Deters, 2006). Although this approach to research has gained interest in producing more conscientious researchers and research participants, the criticism of CBPR from segments of the scientific community question its scientific rigor because of its lack of standardization. One way to address this is by requiring general guidelines and methodologies be adhered to as the dynamic nature of social science research attempts to incorporate ethical standards. The student

researcher will use the CBPR approach by requesting feedback and continual dialogue with the Pueblo Leaders and community members throughout the research process.

Research Design

I have selected an emergent research design because it goes well with a community based participatory approach to research. Community Based Participatory Research is a respectful way to engage with communities throughout the entire research process from the beginning formulation of a research topic to implementation, analysis and reporting. Changes to the study can be made as community input and feedback is received to improve the quality of the research and build respectful relationships. Local cultural protocols are followed to maintain a respectful and culturally sensitive research approach. Before anything of importance is to take place in our Pueblo communities, there is a protocol in place to ask for permission before moving forward. To honor this local protocol, proper permissions were sought on many levels to gauge the appropriateness of the study topic as well as the study population.

Sampling

The researcher recruited participants by providing a face-to-face presentation of the study for the collaborating agencies. Pueblo leaders at the All Indian Pueblo Council of Governors (APCG) and Albuquerque Area Southwest Tribal Epidemiology Center given an opportunity to sign up for the study. Interested tribal leaders' names and contact

information were gathered during and following the presentations. Follow up contact was made depending on the preferred method of follow up with participants. Electronic mail and Facebook messenger was used to recruit participants until the minimum number of 10 was reached. The minimum number of 10 participants was reached with one additional participant making a total of 11 research participants.

I have selected to work with Pueblo tribal leaders because they have the most influence in enforcing future research policies & guidelines that will be informed by the results of this study. In most cases Pueblo Leaders are positions held by male tribal members. There are only a few instances where Pueblo women have held politically driven leadership roles. To overcome this bias, the researcher, upon approval from the All Pueblo Council of Governors, sought to include women from local Pueblos in the study. Participants were recruited through the Albuquerque Area Southwest Tribal Epidemiology Centers/ Native American Research Centers for Health Executive Council and Community Scientific Advisory Council, which is a council of tribal leader appointed representatives that offers guidance on health research occurring in local Native American and Pueblo communities. Inclusion is: Native American Tribal leaders from any of the 19 Southwest Pueblo communities 18 years of age and older who are well established in their Pueblo communities. Exclusion criteria include minors, adults who are unable to consent, and Prisoners.

Research Site

This study took place in the Southwestern United States among the 19 Pueblos of New Mexico. I have selected this site because it is where I come from and where I am deeply invested. Interviews took place either face-to-face at a location agreed upon by the researcher and participant, or through telephone call and internet correspondence.

Data Collection

Narratives were collected from Pueblo leaders by employing semi-formal, face-to-face, internet, or phone interviews. Free, prior and informed consent was garnered before all interviews. Participants were asked for their consent to audio record the interview. One interview was conducted with each participant lasting 25 minutes to 2 hours. The researcher has been conducting research for many years at the local university with Pueblo communities where research is discussed, observation methods ranging from ½ to a full day were recorded through field notes. The period of this study is from April 1, 2017 to April 30, 2018.

Ethics

Local cultural protocols are followed by the researcher according to the Pueblo value of respect for all persons. To maintain continual dialogue with tribal leaders throughout the research process, the researcher has incorporated in-person presentations to two tribal leader organizations and one tribal serving entity to elicit approvals, feedback and recommendations for the study. The two tribal leader organizations include

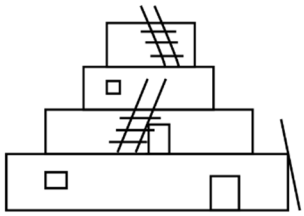
the Ten Southern Governors Council and the All Pueblo Council of Governors. Presentations to these two organizations included a bi-lingual introduction of myself in my traditional Native language and English. Doing introductions in my Native language shows tribal leaders who I am, where I come from, and that I can speak my Native tongue. Using the Keres language when appropriate, helps bridge the cultural, language, generational and gender barriers that still in Pueblo communities and in the context of research.

Being a Pueblo researcher that is deeply connected to my culture and community, I made great effort to use the data that is collected for the betterment of Pueblo communities. Full transparency with my family, elders, community members as well as Pueblo leaders, provides a chance for meaningful collaboration among the researcher and Pueblo communities. Any results and publications from this data will be reported back to and disseminated back to the collaborating agencies.

Data analysis

Audio and or hand-recorded interview notes were transcribed by the researcher and an outside agency. Transcriptions were read in detail to highlight any major themes that arise in the narratives. Because the number of participants is small, counting the frequency of certain responses was used but also any new or important ideas about improving the research process are highlighted. When there was a need to go back to a participant to ask questions for clarification or triangulation, the researcher reached out to the participant via email or phone to make the contact. Participants were given the option

to draw an image or symbol that represents their Pueblo community. These images are dispersed throughout the publication sections. A final “mega-symbol” was created by (@iamlegun.com) representing the coming together of all the Pueblos in one symbol. All data is stored in a password protected computer and any hard copies of consent forms and data will be stored in a locked filing cabinet.



CURRENT STUDY

Context

The research done in this study occurred in the Southwestern United States along the Rio Grande and with Pueblo communities. The Pueblo people are indigenous to this land and have a history that date back to Chaco Canyon. The ancestors to the current Pueblo people were indeed scientist as they laid out a complex astronomical system that played out in the architecture of the community. People often wonder what happened to that inhabitants of Chaco Canyon while I believe we just migrated to different places. I come from one such a place called Santo Domingo Pueblo New Mexico in the books, but we call it Kewa. One of the research participants said what he loved most about his Pueblo community was

"Kewa being the heartbeat of Pueblo country, the capitol. The reputation we have is strong and positive." (E. Chavez, Kewa Pueblo). I come from a Pueblo community that is strong in its ancestral traditions and am honored to be given permission by my parents, leaders, and All Pueblo Council of Governor's to undertake this study.

Pueblo Tribal Leaders

Pueblo leaders are community members who have agreed to take on a leadership role in the community which requires them to keep the best interest of the people at heart in all decision making that is done on behalf of the community (G. Rosetta, personal communication, March 10, 2018). Although most of the Pueblos leaders of the past such as Governors and lieutenant Governors typically have included men, there have been recent changes to include women in political leadership roles. Traditional forms of Pueblo leaders include both men and women and include roles such as healers and society leaders who have demonstrated leadership in their Pueblo communities.

METHODOLOGY

Prayer

To engage Pueblo leaders in a respectful discussion about research, Pueblo epistemologies and local protocols were used as the foundation of this study. A unique aspect of this study is that the research is conducted by a Pueblo woman researcher with Pueblo leaders. This is important because it speaks back to the discourse in the literature that says we as Indigenous people have been researched by outsiders who do not understand our communities and who do not give back to the communities in which the research has taken place. The basic principles of love, respect and prayer are what I have drawn on during the entirety of this study. In Pueblo communities, nothing of importance or significance is done without starting with a prayer. This research started with prayer and maintains a continual dialogue of prayer between the researcher and Creator. Prayers were made to invoke the spiritual element into this work to ask for guidance to do work that would be useful and beneficial to our communities. The knowledge that I have gained through ancestral teachings guided my decision to include prayer in my indigenous research methodology, because every important thing that happens in our village whether it be a school function, board meeting, ceremonial dance, or just waking up and starting each new day begins with prayer.

Permission

Respect for Pueblo protocol begins with asking permission before embarking on any significant life event. This can include asking permission from one's parents, family, elders, community members and leaders. This research began in the same manner with approval being sought by parents, family, elders, community members and tribal leaders. To conduct this research in a respectful manner it was extremely important to get permission.

Family

Consultations with family included asking them their opinion about the topic of *research in Pueblo communities* and the study population being Pueblo leaders. I consider Pueblo leaders to be a protected population and out of respect, I wanted to make sure that I wasn't doing anything that would be offensive to my community. When I asked my dad, Delfino Bird, what he thought about the study idea he reminded me to keep the people and community in my prayers and in all of the actions and work that I do. He guided me in asking for guidance in developing something useful to come out of this work. My mom, Helen D. Bird, was concerned about the sensitivity of the population that I proposed to work with. Mom guidance was to tread with caution but also invoking prayer and blessings of our ancestors to move forward in a good way.

Colleagues

When my parents gave me their blessing I moved forward, and consulted with colleagues via face-to-face, phone, text messaging and Facebook messenger asking them what they thought about my research topic. This gave me an opportunity to discuss with former colleagues I've worked with in the past developing the "Guiding Principles for Researchers Engaging with Native American Communities," which is a document that we co-authored with many colleagues while working at the University of New Mexico Health Sciences Center, Department of Psychiatry (Straits et al, 2012).

Community Members

It was important for me to have discussions with community members about the research topic to get their feedback before moving forward. They suggested getting on the agenda for the Southern Pueblos Council, and the All Pueblo Council of Governors, and Eight Northern Indian Pueblos Councils. These councils have representatives from all the New Mexico and it is usually the governor Lt. Gov. and tribal Council members that attend the meeting (See Appendix A & B). Once I heard the ideas and opinions from community members, classmates and colleagues I moved forward and got permission from my tribal leaders.

Tribal Leaders

Once my tribal leaders approved my topic and gave me their blessing than with their knowledge I moved forward to get on the agenda of the All Pueblo Council of Governors. Once in front of the all Pueblo Council of Governors I asked them permission to move forward with my research topic and I also asked for their feedback in expanding the definition of a Pueblo leader to include women. Interestingly there is a lieutenant governor from one of the Pueblos who was a female. She is a great supporter and signed up to be a participant before the meeting ended.

Including Women as Leaders

A very important unintended consequence that came out of this study revolves around women in leadership roles. As stated previously most of the tribal leaders in the 19 Pueblos of New Mexico are men. We live in a male dominant society where our chiefs, governors and tribal Council members are mostly comprised of men. We as Pueblo women often do not question this experience. There are a couple of Pueblos who have opened the doors to start including women in their politically driven leadership roles. Santo Domingo Pueblo on the other hand, where this research has evolved is a very

conservative Pueblo whose tribal leaders are necessarily men. When I was in front of all the Pueblo governors giving a presentation about the proposed dissertation research I let them know that as I look at them, most of them were men and I asked them permission to expand the definition of a Pueblo leader to include women. There was one governor squirming in his chair as I propose this question. The other governors were very supportive, and I was happy to hear their responses. One governor said there are women in our medicine societies and we consider them leaders. There are also women in our homes we call them our grandmothers who teach us many lessons. Several governors encouraged me and applauded me in my decision to include women in my definition of a Pueblo leader. I remember seeing a couple of my colleagues in the back row with big smiles with fists waving up in the air as if saying "thank you." It was a small victory for Pueblo women.

I asked permission to include women in my definition of Pueblo leaders with in front of the all pueblo counsel governors. Similarly, I received support from governors and expressing that women do hold leadership roles in our communities even if they are elected or appointed to a stated leadership role. It was rare and fortuitous that sitting before me was the Lt. Gov. from Zuni Pueblo who was the only female sitting among the leaders. She called me out on the fact that I said when I looked out at the leaders I saw mostly men. She encouraged me to continue with my study with a warm heart and a big smile.

METHODS

Recruitment

Participants were recruited using a variety of methods including:

1) **In-person presentations** were delivered to two tribal entities including the All Pueblo Council of Governors and the 10 Southern Pueblos Agency. These two entities are led by tribal leaders who represent their respective Pueblo communities. One tribal serving entity, the Albuquerque Area Southwest Tribal Epidemiology Center's Executive Council and Scientific Advisory Committee was also given a in-person presentation about the study to gain support, feedback and recruit participants. All members of the AASTEC ECCSAC are officially appointed by their tribal leadership and are considered leaders in their communities.
2) **Electronic email communication** was used as a recruitment method with approved recruitment language used. Consent form, protocol, and interview questions (See Appendix C, D & E) were sent to several tribal leaders. One tribal leader was recruited via Facebook messenger.

3) **Word of Mouth:** participants were referred to the researcher by colleagues. Recruitment language was sent via electronic communication and interviews were scheduled and completed.

Once a participant showed interest in the study, follow up communication was sent via email along with the research protocol, consent form and interview questions. I felt it was important to send the protocol with the consent form and interview questions so that participants can know the background and rationale of the study and can visually see the study was approved by Arizona State University Human Subjects Institutional Review Board. Another reason I had to send to the related documents along with my recruitment language was to also educate Pueblo community members in the research process.

Data Collection

Eleven interviews were conducted between December 2017 and April 2018. The interview questions consisted of 22 questions related to research, one question asking leaders what they love about their Pueblo community and one final question asking leaders to draw a picture or symbol of what they love. Face-to-face interviews were done whenever possible, otherwise phone interviews were conducted. Consent forms were collected in-person or via email. Participants initialed on the consent form whether they wanted their names used in publications. One participant sent interview question responses via email communication. It was important to remain flexible in scheduling because Pueblo leaders are busy especially during a busy transition period for most Pueblo leaders who often hand over their tribal duties in the middle of December.

A community-based participatory research approach was followed in this study. While the study design was being contemplated, community members were approached along with classmates and colleagues to gauge the need and appropriateness of the subject matter. Many layers of feedback and approvals were sought to adhere to local Pueblo permission seeking protocols. Pueblo leaders were engaged before the IRB approval and will continue to be engaged as the researcher will give a summary report back to the All Pueblo Council of Governors and Southern Pueblos Council will be available for continued consultation after completion of this dissertation.

Approval Pathway

The following are steps listed out numerically to show the many layers of approvals obtained to do this research. This section is repetitive in accordance with Pueblo values of repetition of life lessons in hopes that it will be instilled into our beings. The hope in listing these out is to show researchers how to seek appropriate approvals when doing research with Pueblo communities.

1. Before any research took place, I engaged in dialogue with my parents and family members to gauge their opinions on the research topic and to get their informal approvals to move forward with this work. The first level of approvals gave me feedback and ideas that I was able to consider before moving forward with higher levels of permission seeking. Both of my parents encouraged me to continue doing the work I have been doing with research in tribal communities and supported me in my proposal to interview tribal leaders. I was reminded to always

seek the guidance of my ancestors and Creator as I move forward with this research.

2. Community members were an important layer of feedback and approval seeking. I asked Santo Domingo Pueblo community members their opinions on the research topic because we come from one of the most conservative of all the Pueblos and I wanted to make sure I was not doing anything that would not sit well with my people. I also consulted with colleagues who gave me ideas about selecting the study population.
3. The next level of approvals had to come from tribal leaders in my own Pueblo community. This process also began with prayer with the researcher asking for ancestral guidance before embarking on this process. Local protocols included a formal process of physically going into the Governor's chambers and presenting myself as a community member and a student researcher. I explained the background and rationale for selecting the topic as well as the research protocol in a manner that all who were present could understand. This meant speaking in our Keresan language as well as in the English language. I explained to the Governor, the Lieutenant Governor and their staff of tribal officials that I was a student at Arizona State University seeking approval and feedback for my dissertation topic. I explained the reason why I chose this topic was because of my experience with past research projects in our community. I shared two examples of how research was conducted without our tribal leaders' knowledge or approval. I explained to them that I had seen reports including aerial photographs of our community and I was concerned for our safety. I also questioned a breach of privacy when I saw

aerial photographs of our village with each house categorized as high-mold, medium-mold or low-mold households. I explained to our leaders that it was important that we establish guidelines for our communities so that we can have a say in what type of research gets conducted and how it gets reported out. Our governors felt it was important for me to continue with my study and approved my topic and gave me positive feedback by suggesting I get on the agenda for the All Pueblo Council of Governors. They also informed me that they would be relaying the information to the Tribal Council so that everyone is aware of what I am doing. That was a great day for me knowing that I could move forward with my research topic with the blessings of my tribal leaders.

4. The fourth step in garnering approvals includes presenting my topic in front of the tribal leaders of the Ten Southern Pueblos Agency (SPA) and getting on their agenda for the next monthly meeting which was held in my home community of Santo Domingo Pueblo, New Mexico. In a packed room including tribal Governors, tribal council members, community members and invited guests, presentations were given to our tribal leaders on many different topics including education, religion, services that could be provided to our communities, and my presentation relating to dissertation research. There was a spiritual element underlying this gathering because the meeting was opened with a prayer and included bilingual communication in the Keres language discussing the importance of keeping the best interest of our people in all communication and decisions made that day. As intimidating as it was being a Pueblo woman standing in front of a gathering of all male tribal leaders, I began my presentation

by introducing myself with my native name and clan. This is important in establishing my place and belonging to this Pueblo community. Although English is a common language it's very important to be able to show that I speak my language in establishing my deep-rooted connection to this community. It was at this meeting that I asked for and received permission to expand the definition of a Pueblo leader to include women.

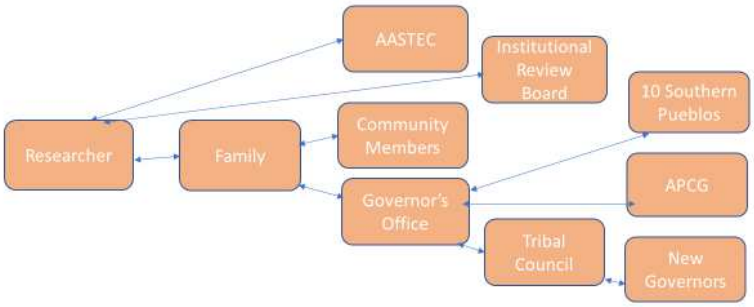
5. The fifth step in garnering approvals included presenting my topic in front of the tribal Governors from all 19 Pueblos of New Mexico including a Governor from Ysleta Del Sur Pueblo in Texas. On November 16, 2017 a meeting was called to order in which the researcher was listed on the agenda titled "Pueblo dissertation presentation." After hearing a brief presentation on the background, rationale and proposed study design, the Governors had an opportunity to ask a few questions. One governor asked how this research was going to benefit the Pueblos. Another said, "Maybe you could help us," meaning I would be able to help the tribal leaders establish research guidelines that were very much needed in the Pueblo communities. I was happy to respond by saying that that is the reason I am doing the study so that I can get a baseline of information to share and report back to the Governors and hopefully began the process of establishing research guidelines. I received the blessing from the All Pueblo Council of Governors to move forward with this research. It is important to note that this would have been a good opportunity for researchers to obtain a resolution for a more formal record of the approval but coming from a community that does not have a written language, a verbal blessing was more than enough for me. When I asked to expand the

definition of a Pueblo leader to include women, I received a special response from Lieutenant Governor of Zuni Pueblo, Mrs. Birdena Sanchez, who said, “I’m here, and I would like to sign up for your study.” There was a small crowd of women in the back row giving me thumbs up and big smiles of encouragement.

6. The sixth step in garnering approvals for this study is to go back to my own tribal leadership because there has been a transition to a new Governor, Lieutenant Governor and staff. It is important to update new tribal leaders since this is the first time there hearing about my study. I again sought feedback and ask for their approvals to continue moving forward with my research. My new leadership will see me when I present the results of my study back to All Pueblo Council of Governors and out of respect I wanted them to know about my study ahead of time. The idea of continual dialogue with our tribal leaders and an important research activity that all researchers should adhere to.

   Figure 1. below shows a visual diagram of all the entities the researcher had to get approvals and feedback from for this research. The entity not identified in the diagram is the relationship with Creator, who was consulted in prayer through all phases of this research.

Figure 1. Study Approval Pathway



Analysis

Qualitative data was collected in the form of interviews with eleven total participants. Eight of the eleven interviews were audio recorded. All interviews were transcribed into Word documents and printed out to be read and coded. Some of the audio recordings were either sent to a transcriber who worked with the University or transcribed by the researcher. As audio recordings and transcripts were read the researcher highlighted reoccurring words and themes from the transcripts. Constant comparison and content analysis and word count were used to analyze the data. Since the research questions were divided into 24 question all responses to each question were compiled and categorized into seven distinct groupings of related questions. Compelling words were highlighted, and quotation marks put around certain words that were profound and highlighted. Many of the answers that asked for yes or no responses were able to be quantified in this analysis.

RESULTS

The shortest interview lasted 25 minutes and the longest interview lasted two and half hours. Five in-person interviews were conducted at locations such as in-home, community library, and workplace. Five phone interviews were conducted due to convenience, work schedules and distance between participant and researcher. One participant opted to email her interview question responses after several attempts and difficulty scheduling during the holiday and flu season.

Participants

Research participants include seven male and four female, adult men and women Pueblo leaders from seven of the 19 Pueblos of New Mexico, USA. At least one pueblo leader from the Pueblos of Cochiti, Laguna, Kewa, Sandia, Taos, Tesuque, and Zuni were interviewed for this study. The youngest participant was in his thirty's and the oldest was

in her seventy's. Some of leadership roles held by participants of this study include; Governor, Lieutenant Governor, Health Board Member, State Representative, Tribal Council Members, Tribal Official, Tribal Programs Administrator, Executive Council Members, Traditional Society Members, Grandmothers, Grandfathers, Moms and Dads. Interestingly, all study participants reside in their home communities. Less than half of the participants gave consent to use their real name in any future publication, therefore their direct quotes are either identified by name or not identified to honor the participant's preference.

Pueblo Leaders Define Research

Pueblo leaders who participated in this study use action words to define research. They use terms such as to gather, to study, to find out more, to compile, and to learn. A simple definition of research would be to gather information to find out more about a topic or situation. One participant defined research as "getting back to the fundamentals of our way of life." Research, to me, means trying to learn of conditions, problems, and the need to determine what is the cause of things that we are having to review."

Former Governor of Laguna Pueblo, Richard Luarkie, defines research using bilingual terms from his Native Keres language and English, "Shramee shraana…be diligent in your assessment." Shramee shraana could be interpreted as take your time and be careful as you do things. Dr. Luarkie goes on to define research as "repatriation of knowledge and wisdom" and in Keres terms, "*Wi'thuuni,"* meaning getting to a place of higher learning and understanding. A person does not have to be old to reach *Wi'thuuni,*

and some people may never reach that point in their lifetime. *Wi'thuuni* takes a critical yet non-judgmental and balanced approach to life and can be reached at any age. When asked whether research is something only done by scientists or academics, Pueblo leaders stated that "research is inherent to our people." "We do research ourselves, we are always asking questions." A female participant answered "Yes, at one time it was the norm to only be analyzed by others, but now there are more community members doing research."

Some Pueblo processes and activities that could be considered research include: stories told for generations, organic farming and "singing to the plants," pottery making, researching our own traditional activities, "our elders state that they're always learning too." We had to learn the lay of the land for ancestral survival, planting, use of natural herbs and hunting and gathering practices. "We have been researchers since time immemorial as is evidenced in Chaco Canyon through the building of the structures and their connection to the stars and planets."

Pueblo research is similar to academic research in that both obtain information and can work to preserve language or help with something of interest. Both look at impacts and can making a difference in a community. Differences mentioned between Pueblo and academic research are that in academic research nationwide comparisons are made and the work is done to create national change. Academic research often has benefits that are offered. Scientific and academic research are different from Pueblo research in that "we don't write them, it is by word-of-mouth what we learn. We don't have a written language, so we don't write it." (Dr. Mary Tenorio, Kewa Pueblo). "Our

own internal research is different and in that it is for the betterment and advancement of our community versus being self-fulfilling to the researcher." There is a difference in terminology and approach; science and academics is based on data and numbers," we are connected to Nature. "Pueblo science is very connected versus the non-native view. The natural laws and spiritual connection to all are so deep that we encourage the elements to gift us with precipitation…rain." (Everett Chavez, Personal communication, March 2018).

Opportunities for Research Collaboration

Ten out of 11 participants stated that there are opportunities for collaboration between outsiders and community rate researchers. In fact, some stated that collaboration is necessary when doing research with Pueblo communities. One participant said, "it depends on the sensitivity of the subject matter." And another said, "we need to define what the protocols should look like that incorporate science models to use as examples. It can't be one-sided any longer."

Current Research and Future Priorities

Many of the Pueblo leaders did mention current research occurring in their communities. Examples given such as studies on the health looking at kidney disease identifying renal disease in diabetics. Whether research mentioned was the youth risk and resiliency survey a youth coalition study forest management, ecosystem, water quality, also research with the special diabetes program for Indians. Other studies include prevention of early drinking for youth and children and one community there looking at the language in the history of old villages and how they lived back in the day. This

community is looking at their ancestral domain in the way farming has been impacted. One community is looking at air-quality and traffic groundwater and water resources and the effect of outside interest on the Pueblo. The environment and wildlife patterns were also mentioned as well as a feasibility study for economic development. Some entities that are were mentioned as collaborators in research were the University of New Mexico and the Southwest Tribal Epidemiology Center.

What Researchers Should Know

When Pueblo leaders were asked "what do outside researchers need to know before doing research in Pueblo communities?" they produced a rich data set of responses. "First of all they have to get permission from the tribal administration or Council." There are proper protocols that need to be followed and there is a need to understand taboos and cultural sensitivity." It's important to have the three C's, consultation, collaboration and coordination through all phases of the research, "says former Governor of Tesuque, Rick Vigil. Another tribal leader put it best by saying quote we have a private life that's different from the outside world. There are levels of confidentiality that we adhere to in the village. And not everything is open to them and they need to respect that." It's important for researchers to go through the process of vetting of what the research questions might be as well as validating outcomes. It's important to know about the community first, it is always better to have a community member who knows the language working with the research team. If a community member refuses to participate

in research don't pursue it. And data gathering does not always happen in the timeframe that is set.

When Pueblo leaders were asked what do native researchers need to know many of them said they need to know "the same thing as is non-native researchers." They need to ask permission from leadership and administration and base it on a real need. There are boundaries of the topics of what they are going to research and they should know who they are and where they come from. "Just because their native they don't get a free pass." All Pueblos have different protocols and "proper channels need to be followed to get approvals and our people need to know what gets published." Again, former Governor Luarkie states, "Shramee shraana," be cautious and encourages native researchers to invoke the spiritual element in the work that they do.

When asked "what's the most important thing any researcher should think about before doing research in Pueblo communities?" tribal leaders most often mentioned the term benefit. They felt and important to have the benefits detailed and to show how it's going to benefit the people taking part in it and if it's going to be beneficial to the Pueblo. The approach needs to be done with respect and you have to connect with people on a personal basis. All researchers must have full authorization by tribal leadership. "They should know about the taboos, about what they should not be asking. Some things are only for our people i.e. traditional ways."

Past Outcomes of Research

Ten out of the 11 participants stated that they do you see benefits from research for their Pueblo community. Benefits mentioned including identification of and prevention of disease, identifying the population that was not getting care at the local health facility, health screenings, hearing youth voice, language revitalization, water rights litigation and economic development.

This study is also interested in what the leaders have to say about negative experiences of research. One participant stated, "does the to stay get ready In the past, research reports were not turned into the tribe." Another leader reported in the past, "we have been researched and the only one that benefits is the researcher. The tribe wants something back." There are also accounts of "anthropologists coming in talking to people writing down very sensitive information that should not have been shared. That research never benefited the tribe."

Although there are many accounts of negative outcomes of research, our leaders do still feel that research is important to our tribal communities. Table 1. lists Pueblo Leaders' priorities and topics for future research. Four main categories come to the surface and the biggest priority for future research topics are health, education, environment and economic development.

Does Your Pueblo Have Research Guidelines?

None of the Pueblo communities represented in this study have research guidelines in place for their Pueblo community. Many of the leaders interviewed stated that guidelines are needed for the protection of our communities and community members. Leaders also agreed that research should be controlled by tribes to have control and oversight. When asked who in their community would be appropriate to monitor guidelines a majority of the leaders said the oversight would rest with the Governor Office and the Tribal Council.

Table 1. Priorities for Future Research Topics

Health	Environment	Education	Economic	Other
Diabetes Cancer -Screening -Fear of Behavioral Health Substance Abuse Alcoholism Women Studies Men's Health Elderly Adverse Childhood Experiences Intergenerational Trauma Traditional Coping Skills "Why are People Getting Sick?"	Land Water Plant Life Environmental Toxins Protect Boundaries	Indian Education Culturally relevant Our Old Ways of Life Language Celebrating Genius Discipline Issues	Economic Development Our economic contribution to the state	Governance "What is it that makes us feel empowered?" "What is it that makes us complacent?"

Suggestions to Improve the Research Process

Regarding the approval process, Pueblo leaders suggested that a committee be formed in the community of educated persons and members from the Tribal Council as well as departments heads or program staff to collaborate with researchers in identifying issues and implementing research with culturally sensitive approaches. When people from the community are included in the research one can draw upon many skills that community members have such as bilingual skills, knowledge of local taboos, timing of certain events in the community and the approval seeking process. All of the Pueblo Leaders participants in this study state that in order to conduct research in their communities the tribal administration including the Governor and the Tribal Council have to approve. Tribal administration has many issues to contend with as they oversee their respective communities and research oversight is one of the tasks often placed on our tribal governors. When asked how often is appropriate to report back to tribal leadership on research activities the most common response was quarterly and sooner if needed. One community leader suggested that it worked in their community to have the Governor and Head Council as private investigators for the study. Leaders suggested:

- having an additional arm to that the research process
- putting together and IRB at the Pueblo
- create guidelines at the Pueblo
- established capacity within the Pueblo
- define the process for authorization

- go through the Governor's office and the Governor is the liaison to Tribal Council
- have a community meeting to inform the community and recruit participants
- establish a primary point of contact in the community
- a resolution can be drafted and signed by the Tribal Council to approve all research

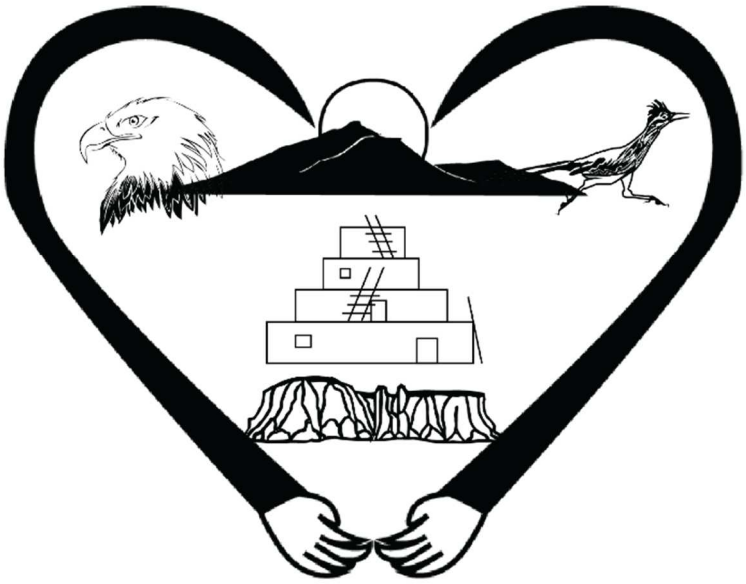
What Pueblo Leaders Love

Tribal leaders are eager to discuss research as well as what they love about their Pueblo communities. Although the main topic of this study revolves around research, I wanted a chance to engage the Pueblo leaders into something positive by ending the interview protocol with questions about what they love. "The people," was the most often cited response. Most of all, Pueblo leaders love the spirit of our people and the sense of community we have in our Pueblo communities. One tribal leader stated, "I love the sense of community that we have and how everyone helps each other out whether it's for

a community event or for traditional ceremonial activities, the whole community comes out to help." Another stated, "I love how we still carry on our traditional way of life" (Rick Vigil, Former Governor of Tesuque). Our traditional and ceremonial way of life and "the fact that we have two languages, the old way and new way of speaking our language." "I'm proud to be SD, It is great to have a place to call home and I never forget where I come from" (Dr. Mary F Tenorio, Kewa Pueblo).

LIMITATIONS

Less than half of the 19 Pueblos were represented in this study. It would be important to get all 19 Pueblos to participate in the future to get a larger pool of responses and feedback about the research process. Another limitation was the use of the English language with people who are fluent in their own Native language. When asking Pueblo leaders to tell me in their own words what the word research means to them, it became apparent that their responses were limited by the English words in their vocabulary and drawing from the English dictionary in their minds. It would be important to have these discussions with the community members in their own language to decolonize our thinking about research and reclaim ownership of our intellectual genius.



CONCLUSION

Being a Pueblo researcher working with Pueblo communities helps to create clear pathways to promote awareness and change. This groundbreaking study addresses some of the past injustices in research that have occurred in our Pueblo communities. Having a local community member engage leaders in a culturally respectful manner by observing local protocols for approval seeking allowed this research to come to fruition and completion. As one of our leaders put it, "invoking the spiritual element" into research methodology promotes the cultural value of being deeply connected to our Natural surroundings, to Creator, to the land and to each other. Being guided by ancestors, community members and Creator through prayer, has promoted the researcher to move forward with caution because of deep love she has for her people. Areas of taboo and cultural insensitivity were avoided on purpose and not the subject of this inquiry.

Pueblo leaders interviewed for this study have common ideas and definitions about research. Using the English language provided some limitations into delving deeper into Pueblo research specifics. It seems that when we talk about research we do often think about the conventional academic term, but once the researcher shared examples such as farming being science many ideas started to flow for participants. Pueblo leaders consider their people natural scientists, researchers and observers of our land and histories. It was exciting for me to hear our leaders making the connection between science and the genius that thrives within our ancestral knowledge and ways of survival. As a Pueblo woman who has done research for 14 years it was validating to hear that the Pueblo leaders do consider research to be very important for our people. The priorities most mentioned were health, education and preserving our language and way of life. It is important to develop guidelines to protect our communities and to take ownership of what gets produced through research. The best way to begin a research partnership is by identifying needs together with the tribe and getting approval from tribal leadership. It is important to have frank discussions by sharing all information with the community and working as equals. If we are to do respectful research engagement in our own home communities it is good to follow local protocols and to teach other researchers to follow local protocols. This study will give Pueblo leaders a chance to experience positive engagement in research that will provide beneficial outcomes, recommendations and awareness to Pueblo communities. Pueblo methodology, protocols, and values can guide scientific research toward a more respectful engagement with Indigenous peoples around the world.

PART 2: BOOK CHAPTER

SHRAMEE SHRAANA: PUEBLO VALUES CAN INFORM RESEARCH METHODOLOGY

My Grandpas, brothers Santiago Leo Coriz and Esquipula Coriz

Kewa Pueblo Circa 1950-1960

Not much is written about the incorporation of cultural values into the research process with American Indian and Alaska Native (AI/AN) populations. Based on the heightened interest and acceptance of ideas such as decolonization, data sovereignty and Community Based Participatory Research (CBPR), we as Indigenous researchers, have an opportunity to change the way we do research in our own communities. This essay aims to 1) provide a brief history of the relationship between the United States government and Pueblo Nations, 2) describe the author's standpoint 3) discuss the main

constructs of a Pueblo research methodology, 4) share examples and suggestions on how to apply these constructs to scientific research and 5) overview of current study done by a Pueblo researcher with Pueblo leaders.

Pueblo Native Americans

Of the many AI/AN tribes represented in the U.S., the Pueblo tribes of the Southwest, have one of the longest history on this continent. Predating U.S. lands claims, many Indian tribes received land grants from the foreign countries occupying North America, including Spain, Mexico, France and Great Britain. Some of these grants, such as the Spanish grants to the Pueblos of New Mexico were later ratified by the United States (Pevar, 2012). For Native Americans of Pueblo ancestry, colonization by the conquistadores of Spain is evidenced by the Governor's canes, which are gifts from the King of Spain that are still in existence in Pueblo's to signify power of authority bestowed upon the Pueblos by the King. The Native populations indigenous to New Mexico were well established long before the Spanish conquistadores entered the region during the seventeenth century (Sando, 1992) states, people forget the Pueblo people were the first People to this continent.

The 19 Pueblos in New Mexico each have their own governance systems (Pevar, 2012, P.258) and are nations in and of themselves. The Pueblos have several distinct languages including Tewa, Towa, and Keresan and continue to operate on clan systems that began since time immemorial. The Pueblo communities have grown accustomed to farming and are geographically dispersed throughout central and northern New Mexico, most notably, along the Rio Grande River. The 19 Pueblos have recently embraced the

Pueblo of Ysleta Del Sur in El Paso, Texas as the 20th Pueblo. It is important to mention the history specific to the Pueblos because of their unique status with the U.S. government and to the lands of the Southwest. Pueblo scholar, Regis Pecos stated that Pueblo communities had research and science imbedded within their subsistence culture by farming and creating arts and crafts from resources in the natural environment such as with pottery, turquoise and shell work (R. Pecos, personal communications, March 16, 2013). This unique population of the Southwest has always been of interest to explorers, researchers, and the public.

Standpoint as a Kewameh Researcher

When we as Indigenous researchers undertake research within our own communities, it is done not only with the academic interests in mind, but also the best interest of the community being studied. The thinking that research should come from the community itself and be addressed along with the community is a notion that is not usually associated with Western science. In the classic scientific method, the science question is developed by the academic researcher and undergoes study without much input from the population being studied and there is much emphasis placed on remaining objective. In our current academic research environment, it is encouraged to look outside the box and find different ways to make sense of our research interests while including input from the study population. I have thus opted to look more closely at how my epistemology as a Pueblo researcher informs my Pueblo research methodology.

Being born on a day of Ceremony among people living on the dirt and into a family of relatives from the Sun and Fox Clans, I began my journey into this world as a

Kewameh; this is the name that we call ourselves as a member of our tribe. This unique beginning helps to form my perspective as a researcher and as a Pueblo woman. Indigenous Standpoint Theory (IST) (Foley, 2003), was a useful in making sense of my unique lens as a Pueblo researcher. Foley's IST incorporates the Indigenous philosophy that there is interplay and connection among the physical world, human world, and spiritual world and that we can maintain our cultural values as we engage in research and academic rigor (Foley, 2006). Indigenous approaches to knowledge may entail protocols that necessarily need adherence to maintain a respectful relationship within the population of interest. Indigenous Standpoint Theory helps to explain how an Indigenous researcher can gauge the acceptability of research activities in a community. It is only through having a deep understanding of the thoughts and values of a community one is researching can one have the knowledge to maneuver local protocols and combine those with the scientific method to engage in a unique form of research with meaningful engagement with Indigenous communities.

The IST philosophy can also translate into similar Pueblo understandings. We as Pueblo people strive to maintain a sense of forgiveness and dignity as we work through the rigor of academia whilst holding the prayers and knowledge of our ancestors in our hearts. Once a Native academic read through the literature regarding American Indians, one cannot help but feel emotional as one uncovers how our Native brothers and sisters experienced life throughout history. The standpoint of a Native American researcher is unique to the roots that inform their knowledge. My standpoint as a female, Pueblo researcher allows me to see research through the lens of the oppressed, knowing in great

confidence that the knowledge produced by my ancestors is also useful knowledge that science can draw upon.

Prue (2014) talks about the standpoint of a colonizer in forming policies that may not be in the best interest of the minority population it serves. Often, we hear that laws and policies are made for the betterment of society, yet when real life situations happen, often those laws and policies work in direct opposition of the core values of minority or Indigenous people. Take for example a recent Health Impact Assessment that was completed in my home community through a grant by the Oregon Public Health Institute and the University of Virginia (Sommers, et al 2016). Since our tribe lies in the Southwest, the first red flag for me arose when I heard that students who had never visited our tribal community were working on assessing the impact of housing on our reservation. I realize there is a lot one can read in the literature and media about our community, but I was interested in seeing how the students would interpret the data that was gathered.

A logic model created by the students from the University of Virginia placed the logic of overcrowded housing as a condition that affected one's mental health. I can see that from a non-Pueblo perspective how that would make sense. Their logic was as follows: Build more houses > eliminate overcrowding > people's mental health would improve. My Puebloan lens immediately thought about the hundreds of years that we have lived in extended family kinship networks where multiple generations live in the same household while supporting one another in the quest for survival. Upon reviewing the logic model, I immediately wondered, "What happens to the grandmother when all of her children and grandchildren move out of the family home and into the new housing

area?" "What happens to the mental health of the grandparents who won't hear the pitter patter of little feet running through their household anymore?" "Who will speak to the children in our Native language if no one is home to teach them?" Living at the new housing area will likely mean the parent or parents will have to take an outside job to pay the rent. The students from the University of Virginia did not have enough information about the history of our civilization and how living together in extended family households has been protective for our children, our culture, our community and our mental health and well-being.

I share the above example to highlight that facts the researchers have their own views, values, and lenses that guide their work. Researchers may not see their interpretations as being biased. Linda T. Smith (1999) calls it "*research through an imperial lens*." The products produced by this lens of research may cause unintentional (or intentional) harm to the populations that are the subjects of their inquiry. I bring standpoint theory into the discussion here, to shed light on the critical lens that I read through as I review the literature on American Indian health research.

Once we put the well-being of our children, our communities and our families at the center of everything we do, the research questions reveal themselves and so do the indigenous methodologies that have been embedded into our cultures for centuries. (L. Pihama, Personal Communications, October 29, 2016)

Pueblo Research Constructs

"Whenever any researcher works with Indigenous communities, there is a protocol that must be followed, and that is usually controlled by the tribe or the community" (Lambert, 2014).

To inform the development of a culturally sensitive research approach for Pueblo communities, I have drawn upon fourteen years of research experience as well as the lived experience of being a Pueblo woman to consider some major constructs that would be necessary in a Pueblo research methodology including Indigenous knowledge and Pueblo worldviews. The following four areas are what I consider integral to include in a Pueblo research methodology.

1. *Spirituality and Prayer*

Before a Pueblo person undertakes any project, task, or ceremony of importance, one must connect with the spiritual realm of our ancestors and Creator, through prayer or through a moment of silence as we make an offering while asking for blessings for the world. In order to elicit strength, ideas, blessings and support, Pueblo people have called upon higher powers knowing there are other realms of consciousness and understanding that one can draw upon. When one grows up with ancestral knowledge of connecting with spirit through song, dance and prayer, undertaking the task of research is no different than preparing for ceremony. For the best possible outcomes of a research project for the community it serves, it is a common Pueblo methodology to incorporate

prayer and call upon all Indigenous knowledge systems for the betterment of the people it serves.

Western science has begun to show evidence that the power of prayer is real and scientifically supported. It has been shown that patients engaged in prayer can increase healing and positive outcomes for individuals and their health (Brick, et al 2012). The Fetzer Institute along with the National Institute on Aging have been studying the impacts of religion and spirituality through its assessment tool titled, "Multidimensional Measure of Religiousness and Spirituality" (MMRS) (Neff, 2006). This tool has a brief version (BMMRS) that was used in alcohol and addictions research with American Indian populations (Venner and Feldstein, 2006).

Researchers engaging in prayer may be a novel concept in the realm of Western academic science, but when it comes to a researcher informed by a Pueblo epistemology, prayer informs our ontology. Shawn Wilson's "Research as Ceremony" (2009) reminds us that an Indigenous researcher has his/her own axiology and epistemologies to draw upon, from the conceptualization of the research design to the implementation and dissemination of the results. Other Indigenous people such as the Native Hawaiians and the Maoris, are also looking at how we relate not only as individuals in the research we engage in but also as individuals in the larger scheme of our existence and in creating knowledge (cite sources).

2. *Amo Hobah: Love and Respect for the People*

My upbringing as a Pueblo female informs my ontology and way of engaging in the world and as a researcher. The deep level of respect for the people that comes with being taught by our elders to "love everyone and look out for one another" guides my

actions as I conduct my work. The values I place in the interactions I envision with my research participants are based on what I have learned about being a Pueblo woman. The respect that I have learned to give to my elders, my ancestral teachings, my language, my culture, myself, all inform a Pueblo way of approaching research and science.

Pueblo leaders are individuals who are members of Pueblo communities that serve in various capacities representing their communities. In most Pueblos, once a tribal member (usually a male) becomes a high-ranking leader such as a Governor, Lieutenant Governor, Church Mayor, or War Chief, that person remains a member of the tribe's tribal council for the rest of their lives. Being a Pueblo leader entails life-long commitment of service to one's people. Being a Pueblo researcher, I understand the role that our tribal leaders play in our communities and I therefore, must consider the protected status of Pueblo leaders as research participants.

Suina (2017) reminds us that there are many nuances to consider when engaging in research with Pueblo communities that don't always fall in line with the Western academic way of doing research. For example, asking too many questions may be seen as being too invasive or nosy. If the type of data that you are collecting is stigmatizing to your community, how will you live knowing you have affected all your relatives in a negative way? Relationality is key, when engaging in research with Pueblo communities. Our academic colleagues across the waters have a Kaupapa Maori Theory (Smith, 1999) that guides Maori researchers in their actions and ways of being as Maori researchers, who have the best interest of their people at the heart of their research.

3. *Shramee Hobah: Following Cultural Protocols*

Local protocols can inform research methodologies to create culturally sensitive and appropriate research. For any research to be culturally appropriate in a Pueblo community, the researcher must be knowledgeable of, have respect for, and follow local cultural protocols. Local protocols, which guide proper behavior, may have been in place in the community for hundreds of years. I found that in doing research within my own Pueblo community meant I had to follow local protocols as a Pueblo woman. First, I had to pray and ask for guidance. Then I had to physically go into the Governor's chambers to present myself and my dissertation topic as I asked for guidance and permission to move forward. I was fortunate enough to be able to converse in Keresan (our Native language) and English as I explained the background, purpose, and rationale of the study.

I realize not every researcher feels it is a requirement to get permission from their fellow community members, elders and tribal leaders before moving forward with their research. For me it is of utmost importance to garner approvals because I respect my community members and leaders and would not want to do anything they consider bad for our community or something they would not approve of. We live in such a close-knit community I wanted to be sure my research was approved and I had tribal approval before conducting any research.

4. *Make Sure the Research is Beneficial to the People*

When one grows up with great value placed on learning to love one another and having to take care of each other, it is necessary to think about the risks and benefits of any community undertaking. Research done in Pueblo communities has not always been a benefit to the community. Community members often complain about people coming around asking questions and collecting data but never seeing anything good come out of

it. It is very important for me as a researcher and as a Pueblo member to know that the work I am about to embark on is appropriate and worthy of everyone's time and will be useful to my community. I, along with other Pueblo researchers, (Chosa, 2017; Suina, 2017) have grown up hearing our elders say, "Go out and get an education, and when you're done, come back and help your people." I heard that enough times throughout my years growing up in Santo Domingo Pueblo, that I internalized it and feel a deep sense of responsibility to protect my people, my culture, and my community. I wanted all the years of my education and my dissertation topic to be useful to all Pueblo communities, not only mine. If ever there was a time when I wanted all my years of education to be able to help our people that time is now. This principle is similar to the tenets of Tribal Critical Race Theory (Brayboy, 2005) and Kaupapa Maori (Smith, 1999); when one puts the tribe at the center of everything we do as researchers, it is our moral and ethical duty to make sure our work benefits the people.

Application of Pueblo Constructs in Western Scientific Research

The following bulleted list are examples of ways Pueblo constructs can be applied in research:

- Respect can be applied to the scientific method starting with the conceptualization of the research design and requesting approval from tribal leadership.
- Incorporate community input into the development of the research questions instead of developing the questions all on your own.

- Elicit feedback from the population where the research is to occur to gauge the appropriateness of the methods and tools you are proposing.
- Be cognizant of people's time and environment, especially during days of cultural observation.
- Researchers working with Pueblo communities will have better success if they honor the wishes of their host tribe when it comes to presentation of data and results.
- Co-developing Memorandums of Understanding, Data Sharing Agreements, and Tribal Resolutions are all official ways researchers can honor a tribe's wishes and incorporating those wishes into the research partnership is a great way to build trusting relationships.
- Respect can be observed in the dissemination of results and the types of data one reports on by having continual dialogue with tribal leaders as to the appropriateness of the presentation of research results.

When incorporating love and respect for your research participants and the communities they come from, one draws upon the ethical value of compassion; compassion to consider the implications of the data not only on your research participants, but upon the larger community.

Principles of Culturally Sensitive Research

It is important that research proposals with any AI/AN communities are built on a foundation of respectful communication. In Pueblo communities it is important to ALWAYS approach the tribal leadership, in this case the Governor of the tribe, before

beginning any research process. For example, the Navajo Nation has a very active Research Review Board lead by a Dine' woman who takes community, culture, and the environment into account as the Board reviews research, making sure protections are in place for research participants and their community (Beverly Bowman, Personal Communications, May 2014). Similar to the Belmont report of 1979, the main concept of "Do no harm" applies to research with Native American tribes and populations. Some added layers to do no harm may include making sure the research is beneficial to the community and hopes of positive interactions moving forward.

The National Congress of American Indians issued a guidance document for health researchers in 2012. This document discusses many important aspects of culturally sensitive research with American Indian and Alaska Native populations. A similar document created at the University of New Mexico Health Sciences Center along with several partners such as the Albuquerque Area Southwest Tribal Epidemiology Center in producing guidelines for researchers working with Native American communities (Straits, Bird, Tsinajinnie, Espinosa, Goodkind, et al 2012). These two documents complement each other in providing a foundation of understanding in what principles guide culturally sensitive research. Both share common elements of social justice and share vignettes of real life examples of research happening out in the field.

Pueblo Values Can Inform Research Methodologies

Research Design

Incorporating local cultural protocols into research reflects elements of Community Based Participatory Research (Minkler & Wallerstein, 2011, Wallerstein and

Duran, 2006). Community Based Participatory Research involves eliciting community input and feedback from the conceptualizing of the research question all the way to the dissemination of the results. It also requires continuous involvement in the research process by all collaborating entities forming long-term relationships that support future research collaborations. I argue that research relationships should not end after the dissemination of results is completed. Once a deep and respectful relationship has been developed, it is important to foster continued engagement and communication with the community and its members long after the project has ended. These fall in line with Pueblo values of having respect, caring, and reciprocity. If cultural protocols are respected and followed, the research will more likely be supported in the community.

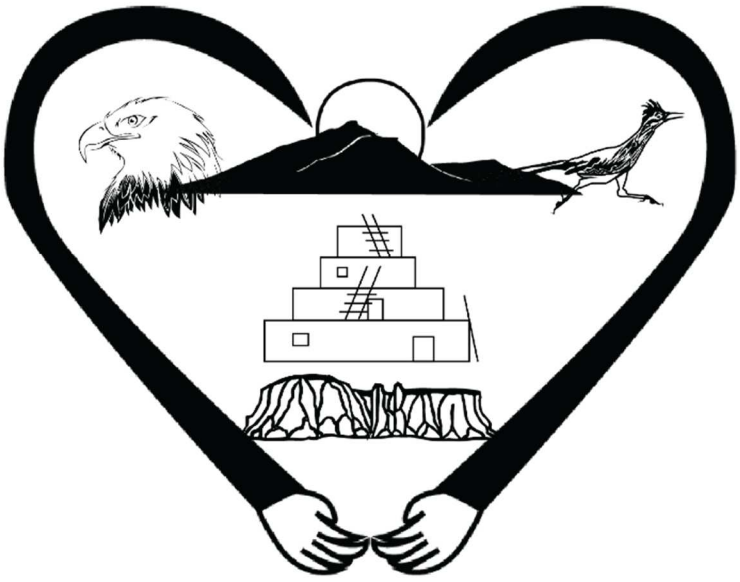
Research Analysis

Triangulating the data with community members and research participants is one way of incorporating the construct of respect into the data analysis process. Going back to the participants and asking them if their story has been interpreted in the right way is done out of respect to the participant but also done in Western science to maintain rigor. This approach is similar to CBPR by including the study population in every aspect of the research process. There is a similar concept among Indigenous researchers from Aotearoa called Kaupapa Maori and it incorporates community interest and involvement from beginning to end of the research process. An example of this is holding focus groups with research participants to gain input on proper levels of analysis and going back to them again once analysis is complete to ask if the results make sense to them (Hudson, Smith Beaton, Toki, Milne et al. 2016).

Dissemination of the Results

One way to incorporate the Pueblo construct of cultural protocols into the dissemination of the results process is to ask permission from tribal leaders before sharing the results or providing a presentation to anyone. Often, researchers fail to provide continuous dialogue with the tribal leaders of the communities they are engaging in research with. Even if the research was supported through a community champion, it is always proper to give updates to the tribal council or tribal leadership on a continual basis. When I am ready to share the results of my study, I will go back to my tribal leaders and provide tailored bilingual, oral presentations, as appropriate to the different audiences that could be impacted by my study. This incorporates the concept of respect for the people in that I will not do research with Pueblo communities without sharing the information gathered back with Pueblo communities. In providing oral presentations, one opens a space for discussion and continued feedback. It is also important to note that as a researcher engaging in culturally sensitive research, if the community does not approve of the research results to be disseminated, you have to honor and respect their wishes. It is important to have all of this put on the table for discussion from the very beginning of the research process.

STUDY



The current study builds upon prior work by the author and Indigenous researchers and allies. The goal was to develop a learning tool for researchers working with Native American communities that would give them a foundation of knowledge to work from when engaging in research with communities not of their own. The group also realized that not only researchers but tribes themselves could use some tools to help guide their research decision-making processes. Most of the scientific literature written about AI/AN populations was authored by people who are not Native themselves. This study aims to get a baseline of information from Pueblo leaders to see what research means to them in their own words, to hear their priorities and perspectives of research, and to get some guidance and suggestions into ways to improve the research process. The goal is to

go back to the Pueblo leaders with a summary of research results and use the results to develop research guidelines and policies for Pueblo communities.

Pueblo Protocols Inform This Research

This research is conducted on a foundation of Pueblo teachings and respect for local protocols. All significant activities in Pueblo communities begin with prayer and thus, prayer leads this inquiry into Pueblo leader definitions and perspectives of research. The local protocol of permission seeking is another important Pueblo process that when carried out in proper Pueblo protocol, symbolizes respect for one's elders, traditions and loved ones. Maintaining a continual spiritual connection to the ancestors and Creator guiding this work helped keep the principal researcher humble do the whole process. This was my chance to finally give back to my community after having spent a significant amount of time in higher education and academia and away from my community. Engaging in research and asking for permission from my tribal leaders was a humbling process and have grown in confidence as a Pueblo woman to share my voice among Pueblo leaders to help Pueblo communities. Growth in a Pueblo community we are taught the value of loving one another respecting one another and taking care of one another. It is those same values that guide this research and reminds me to tread cautiously do every step the protection of my community at the center of my work.

Participants

Study participants are eleven adult Pueblo leaders representing 6 of the 19 Pueblos of New Mexico, USA. A person is considered a Pueblo leader when they have

taken on the responsibility of a leadership role in their community which requires lifelong commitments to be caretakers of the community. Pueblo leaders in this study included former Governors, a Lieutenant Governor, Tribal Council members, former War Chief, Tribal Official, Health Board member, grandmother, executive committee member and state representative. The Pueblos represented in this study include Cochiti, Laguna, Sandia, Tesuque, Kewa and Zuni. Study participants included 4 females and 7 males.

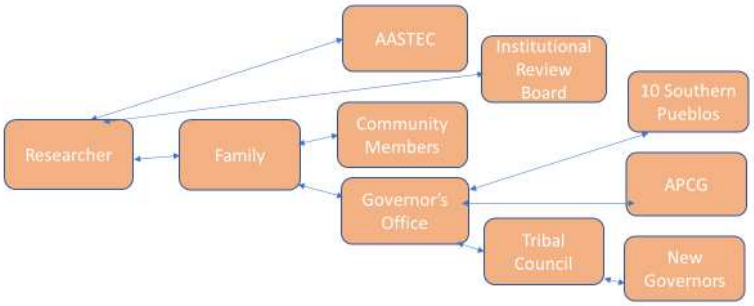
Methods

The "*Approval Pathway*" for this study (See Figure 1. below) included five layers of permission seeking to form the basis of respectful engagement with Pueblo community members from the beginning of this study. Family members, community members, colleagues, local tribal leadership, Southern Pueblos Council, and the All Pueblo Council of governors were consulted to elicit feedback and gain approvals to move forward with this research. Face-to-face, phone, and email communication were used to recruit participants, collect data, consent forms and enhance communication for the study researcher and participants.

Whenever possible, interviews were audio recorded and transcribed into word documents for qualitative data analysis. Responses to the 24 interview questions were compiled and analyzed using constant comparison, coding and theme generation, content analysis and word count analysis. The final question in the interview protocol asked Pueblo leaders to draw a picture of the symbol of something they love. In response to the final question in the interview protocol where participants were asked to draw a symbol of something they love, most of the Pueblo Leader participants chose to verbally

say what their temple was in the author commissioned a local Pueblo artist (@iamlegun.com) to draw the symbols created for this study.

Figure 1. Study Approval Pathway



Study Results

None of the pueblos represented in this study had research guidelines in their communities. Many of the Pueblo leaders cited negative outcomes of research in the past. It was decided that in the past archaeologists would come into our communities and gain access to information from local community members who shared sensitive information in books and report that were not beneficial to the community. One leader stated that the answers to research questions are skewed for example people look upon us as poor because of the data that is collected but we are not for because of our sacred way. In the past people's all information to get by now people have a moral conscience. Although there are many negative outcomes to research that recited Pueblo leaders do still feel that research can be of benefit to Pueblo communities. Tribal leaders feel that tribes should

take ownership of the research and all agreed for the need to develop guidelines for research in our Pueblo communities.

Tribal leaders define the term research with action words such as gathering, looking for or finding out information to determine a cause or find out more about a topic. Tribal leaders agree that research is not something that is only done by outsiders or academics, but it is something that's been done by our Pueblo people's time immemorial. In the past people came into our communities and did research without community involvement and now leaders are ready to discuss the need to develop protocols and guidelines to protect our community members. Tribal Leaders want research that the beneficial to our communities and they want our local call cultural values and protocols to be respected in the research process. Leaders agreed that there are many Pueblo processes and activities that are considered research such as recounting stories told for generations to know what kind of food to serve for certain these days. Sustaining our lifeways and traditional activities are included among examples as well as singing to plan and knowing the lay of the land and how to use natural herbs. One Pueblo leader recounted the method building structure at Chaco Canyon that aligns with the cosmic map in the sky. Daily tasks such as organic farming and pottery making and even something as simple as telling time according to the sunrise and sunset are all examples of Pueblo processes considered research.

The most important thing that Pueblo leaders want researchers to know is that they must seek permission for any research project. They want the research to be beneficial to the people and you're going to get we are asking for you have to connect

with the people on a personal basis. It's important to consult with tribal communities to come up with the research questions together and be open and honest in all communication. Pueblo leaders want researchers to know that there are boundaries regarding certain topics and not everything is open for inquiry. "On one side Pueblo communities are just like everyone else but we also have a private life that's different from the outside world. There are levels of confidentiality that we adhere to in the villages and not everything is open to them." (Elder, Male, Tribal Leader, Cochiti Pueblo) Research doesn't always happen according to the timeframe that researchers expect because there are activities that occur in Pueblo communities that often take precedence over research timelines. It's important to validate that outcomes and consult with the community members for feedback in the interpretation of the results. It's important to know the community before any researcher goes into a community because there are taboos and cultural protocols that are important to honor.

The summary of all the information given and shared by Pueblo leaders is like an invaluable booklet of knowledge. Many of the Pueblo leaders are highly and deeply connected to their community into their cultural traditional activities in the community. This gives a deeper level of commitment and sense of responsibility to do the right thing for people. Many suggestions were given by Pueblo leaders on the ways to improve the research process. A few of their suggestions are highlighted below.

Regarding the approval process Pueblo leaders suggested that a committee be formed in the community educated persons and members from the tribal Council as well as departments that to all collaborate with researchers in identifying issues and

implementing research with culturally sensitive approaches. When people from the community are included in the research on of the able to draw upon many skills that community members have such as bilingual skills, knowledge of local taboos, timing of certain events in the community and the approval seeking process. All of the Pueblo leaders stated that in order to conduct research in their communities the tribal administration including the Gov. and the tribal Council to approve. Tribal administration has many issues to contend with and research oversight is one of the task often placed on our tribal governors. When asked how often is appropriate to report back to tribal leadership on research activities the most common response was quarterly and sooner if needed. One community leader suggested that it worked in their community to have the Governor and Head Council as private investigators for the study. Leaders suggested the following:

Table 2. Suggestions for improving the research process in Pueblo communities

- having an additional arm to the research process with tribal oversight
- developing a Pueblo IRB
- create guidelines for each Pueblo
- build capacity within the Pueblos
- define clear process for approvals
- the Governor's office is the liaison to the tribal Council
- have a community meeting to inform the community and recruit participants

- establish primary points of contact in the community and with tribal leadership
- a resolution may be drafted by the tribal Council to approve all research activities

Although Pueblo leaders agree that research should be controlled by tribes many mentioned that each tribe is different and so that would be important to have local oversight in each Pueblo community. Suggestions were given that the All Pueblo Council of Governors work with the Albuquerque Area Southwest Tribal Epidemiology Center and the Southwest Tribal Institutional Review Board to start a dialogue in developing a formal oversight process for Pueblo research. The results from this study will be returned to the Pueblo leaders and recommendations given in hopes of continuing to work to establish guidelines and protocols for Pueblo communities.

It is apparent that Pueblo communities will continue doing research into the future. Pueblo leaders identified health as a leading priority for future research. Health, language, economic development, and environment were also mentioned as important priorities for future research for Pueblo communities. Former Governor of Laguna Pueblo, Richard Luarkie, Ph.D., states that a future priority in research should be "celebrating the genius of our people." Other tribal leaders stated they wanted to know what motivates us and where our strengths areas we move forward in sustaining our communities, our culture and our languages.

Our Pueblo Leaders Love Us

One of the things that I've always found unique about Pueblo communities is the way that our leaders engage and communicate with us community members. I read in the literature that having tribal leaders show they care was a protective factor for American Indian and Alaska Native youth (Pharris, Resnick & Blum, 1997). I agree, because having Pueblo leaders tell us that they love us and that they care really gives us a secure foundation to know where we belong and where we come from. When asked what they love about their Pueblo community, Pueblo leaders responded most often by saying that it was the people that they loved the most and the sense of community and the closeness of extended families. The importance of the culture and traditional religions activity permeates tribal leader responses for what they love about their community. Dr. Luarkie states that "The spirit of our people is a profound and beautiful spirit woven through all the communities. I love the cornmeal, pollen, and our prayers. We still have the connection to the Creator." Other Leaders state, "The cultural teachings we have are still here, Kiva and Hunter societies." "There is a reciprocity between individual and tribal responsibility and obligation. The sense of community and relationships we have, gives us a sense of interdependence." In summary, Pueblo leaders who participated in this study named the people, language, traditions, and prayer as what the love most about their Pueblo communities.

DISCUSSION

We must incorporate respect for local protocols into our current research paradigm. It is high time to address many of the negative consequences of past research efforts in

Indigenous populations. Researchers and participants can learn from the research process and from each other to have meaningful engagement and a sense of respect for one another. Respectful research engagement has the potential to empower our communities to live in harmony within the world and with respect given to their cultural core values (Bird, 2015).

We as Indigenous researchers are beginning to assert our dual knowledge systems, Western and Indigenous, and merging the two approaches to benefit our communities. With a more culturally sensitive research approach, it is important to incorporate community input and feedback from the initial drafting of the research questions with continual dialogue throughout the implementation, analysis and reporting phases.

CONCLUSION

Pueblo scholar Anya Dozier Enos (2017) uses the corn as a metaphor for life. The corn plant is very important in many ways to Pueblo people such as for food, spirituality, artwork, and prayer. If we nurture the corn and take care of it, it will take care of us by providing nourishment. I feel the same way about research. If we learn all we can about research, nourish it and take care of it, it can help take care of us by providing insights into topics we choose to study. Incorporating the values of Pueblo people into current research practices with Pueblo populations can enhance researcher and participant engagement in Pueblo communities. Incorporating Pueblo peoples' definitions, ideas, and prioritized engagements with research can inform future work and research with and within Pueblo communities. If we can reclaim our research as L. T. Smith writes about

in Decolonizing Methodologies, we can also reclaim the excitement of learning about the natural world and our culture all within arm's length of science.

We have come a long way in the history of Indigenous research, from being researched *on* to conducting research *with*, as we have moved from de-colonizing methodologies to creating Indigenous methodologies and describing our Indigenous epistemologies. Some key lessons take us back to the basics such as ensuring we as researchers instill the principles of respect, humility, and beneficence, as we engage in research that benefits the communities we work with. It is an honor to have the opportunity to have AIAN participants share openly about their life experiences which include ancient knowledges. Honoring both the differences and similarities in our cultural values as Indigenous people and researchers can increase levels of cultural sensitivity in the research we undertake. By building in continual dialogue with the community members such as, leaders, elders, and youth, research engagement with AIAN communities can do much to remedy historical injustices in research (Straits, et al, 2012; NCAI, 2012). These are exciting times in the field of research. Now is an opportune time for Indigenous researchers to reclaim and recreate paradigms for socially just and conscientious research with Indigenous populations.

A main point that keeps coming up is the need to go back to the people in our communities and have discussions with them about research and how they want to address the topic of research going forward (Smith, 1999). As a Pueblo researcher, I have the unique opportunity to incorporate Pueblo core values into the research that I conduct with Pueblo people. Having been trained in Western academic research methods, it is hard to deviate from the scientific method in developing Indigenous methodologies.

Starting with what's similar among research core values and Pueblo core values, can give Pueblo researchers a foundation to build upon when developing Indigenous methodologies that are congruent with their cultural core values while aiming to be true to the study of science and research.

We as Indigenous researchers have respected the value of Science but has scientific research reciprocated that respect by valuing our input? Are Tribal Nations honored in opting to keep their data private and not necessarily contribute to scientific knowledge just for knowledge's' sake? We have found common values of respect, beneficence and justice among the Pueblo and scientific research communities. These common values can guide our future research endeavors as we address the major differences that still exist, such as the assumption that it is necessary to share our research findings with the world.

SECTION 3: POLICY PAPER

RESEARCH GUIDELINES ARE NEEDED IN PUEBLO COMMUNITIES

Executive Summary

Protections in research have become an important topic given the large numbers of studies being done in underrepresented populations, including Indigenous, American Indian and Alaska Native populations. L.T. Smith (1999) talks about Indigenous populations being the most researched people on the planet. Unfortunately, some of the research has resulted in the publication of data and information that did not turn out to be in the best interest of the tribe and its tribal members. When much of the focus of research in Native populations leads to resulting reports that highlight high rates of chronic diseases, such as diabetes or other indicators such as poverty or rates of trauma and PTSD, what can end up happening is people generalize the information to all Native communities which can be stigmatizing to the individual communities being researched and to all Native populations. We have all heard of the "drunken Indian" stereotype, which was perpetuated by a research study in Barrow Alaska that reported rates of alcoholism in a sample taken from one Alaskan community (Foulks, 1989). from the study based its results on a survey of only a 10% sample of community members aged 15 years and older, providing no data about the rest of the population, which included many abstinent tribal members. Research information can get blown out of proportion and stigmatize an entire community and population of people. Native American populations are leading in many of the negative health indicators related to social determinants and

related health issues, we must keep in mind that resilience and survival are also critical components (Weaver, 2014) and we must not lose sight of what keeps us strong.

Much of the past and current practices in research conducted with American Indian populations have not involved the communities being researched in any of the major decision-making processes usually conducted at the outset of a research project. The resulting literature on American Indian populations highlight high rates of negative health indicators such as alcoholism, poverty, suicide, diabetes and trauma (Bassett, Buchwald, & Manson, 2013). It is imperative that tribal nations take control of the research conducted in their communities by establishing strict guidelines and procedures for all researchers to follow when requesting to enter the tribal community for the purposes of conducting research or gathering data. Projects proposed with tribal communities and American Indian populations often are for purposes that are for the sake of research institution and gaining scientific knowledge with little accountability to the people who may be involved.

Some Tribes are taking ownership of the research process and management of their data by development of research policies with their communities' and Indigenous cultural preservation in mind (Lambert, 2014). This policy paper is intended to create awareness of the importance of establishing and setting clear research guidelines for the protection of Pueblo communities and tribal members. A brief history of research protections will be followed by examples of injustices in research that lead to the need for tribal leaders and community members to take control of the research practices occurring in Pueblo communities. This paper will discuss examples of what other tribes,

institutions, and tribal serving entities are doing by taking an active role in research activities involving Native American communities. This paper will conclude with research examples and policy recommendations specific to Santo Domingo Pueblo so that tribal leaders can become informed of the importance of and high need for the establishments of guidelines and policies for research.

Scope and Severity of the Problem

One of the most famous injustices in research comes from the Tuskegee Syphilis Study conducted by the United States Public Health Service between 1932- 1972 with over 400 African American men infected with syphilis being observed as they suffered the natural progression of the disease even though a medicine (penicillin) was available (Jones, 1993). The study was done to see the disease and its symptoms as it progressed, but was not intended to be a study that would treat these people or help them heal from their disease or symptoms. Nurses were recruited to go into these southern communities and recruit research participants by telling them they would receive a free physical examination. Participants were told they had "bad blood" once they tested positive for syphilis and were followed but never treated. The participants knowingly gave of their blood samples thinking they were being treated for having "bad blood."

The leading report on the subject of human protections in research is the Belmont Report, published in 1978 by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research (National Commission). The National Commission, established by the U.S. Congress in 1974, was charged with establishment

of research guidelines that guide ethical involvement with human research participants (Emanual, E. J., 2011). The Belmont report highlighted the need for ethical considerations in research and laid forth a foundation for protecting human research participants.

Although research in general had issues to contend with, it is important to turn the focus on Native American populations as more and more research is being conducted with American Indian and Alaska Natives. Lomawaima and McCarty, (2006) write about the history of Indian education including boarding schools and the effects educational policies have had on Native American children. Until 1924, American Indians were not birthright citizens of the United States and forced policies of assimilation through educational systems give us many clues as to the intent and reasons for the United States government to collect data on Natives (Lomawaima1994). We have come to a point in history where there are new opportunities for tribal nations in the way they deal with the U.S. and other governments, tribal nations, and their own communities. Among the relevant areas of social determinism and tribal sovereignty is the topic of research and data ownership. With the amount of research going on in Pueblo communities, it is imperative that we address the high need for a more conscientious approach to the development of strict research guidelines for American Indians and for Pueblo communities.

Another major example of research injustice is the case of Indian Health Services sterilization practices on over 3,000 Indian women in the years between 1973-1976, without obtaining informed consent from them (Dillingham, 1977). Albuquerque Area

was one of those IHS areas where many Native women were unknowingly sterilized and were not given essential information as to what the procedure was and that it was irreversible. It is shocking to know that hospitals in our area participated in these practices without our people knowing about it.

The latest well published research atrocity occurred with the Havasupai Tribe and Arizona State University researchers. In an unprecedented case, the Havasupai Tribe filed a law suit against Arizona State University Board of Regents for improperly using tribal members' blood samples for genetic research for a purpose that was different from what the research participants initially consented to (Drabiak-Syed, 2010; Mello & Wolf, 2010). The major issue with the Havasupai case was that although the researchers did get consent from participants to collect blood samples and use them in research intended for the study of diabetes, the unethical behavior came in when one researcher used the blood samples for another unrelated research project on genetics, which they did not have participant consent for. Consent forms collected for the earlier study are only valid for that study. If the researchers wanted to use the blood samples for the new study on genetics, the correct form of action would have been to go back to each participant to get their informed consent and new signatures for the new study. Once the tribe and research participants caught knowledge of what happened, they demanded to have their blood samples returned. This incident has left a feeling of mistrust of researchers among many Native American people. These above examples show the dire need for the development and establishment of research guidelines for researchers and outside entities engaging with tribes and tribal data.

Some of the positive outcomes of the Havasupai V. ASU case was the establishment of a Native American Research Consultation Policy, approved by ASU in 2016 to aid in positive partnership and collaboration with tribal entities (J. Moore, personal communication, January 13, 2017). ASU has also instituted a cultural review process for any research dealing with tribal entities or Native American research participants. The university IRB receives the initial research proposal, but then flags for cultural review once tribal entities are mentioned. This new procedure allows for an in-depth review by Native American staff at ASU to allow for special considerations about cultural sensitivity and community protections.

Research in Pueblo *X*

There has been a long history of research and documentation of tribal specific data through the U.S. Census information and IHS health records. In 2009, a Behavioral Risk Factor Surveillance Survey conducted in the community in partnership with the Albuquerque Area Southwest Tribal Epidemiology Center (AASTEC, 2012). Data from that community assessment of adult tribal members living on the reservation lies with the AASTEC staff until there is a time that the tribe wants access to that data. Hard copies of the data and reports have been delivered to past tribal Governor's. Since that time, the tribe has entered into a data sharing agreement with AASTEC and continues to engage in health research opportunities.

Two research projects conducted recently *in X* Pueblo (identity protected), discussed below, have raised concerns for me as a public health professional and researcher. There is a high need for tribal leadership to become aware of the research

that is occurring in and about the community as well as the need to establish research guidelines to assist the tribe and outside entities in finding appropriate ways of engaging in respectful, mutually beneficial research with tribal community members.

1. Community Health Impact Assessment (HIA)

The first project was based out of the Housing Authority for a Community Health Impact Assessment to be conducted by the University of Virginia and the Oregon Public Health Institute. The study has been on-going for the past couple of years and has now ended (Somers, Sturz, Jones, et al 2016). The HIA was funded by the Oregon Public Health Institute and included advertising a public Health Assessment Workshop at a local Pueblo. Although efforts were made to involve the community in the research process, meetings in the community were not well attended, and the university researchers attempted to get community input through development of a community advisory committee. Several community members were recruited during a workshop in the community to assist in gaining community buy-in. Many people attended the HIA workshop where maps and housing development plans for the tribe were presented.

Several issues arose as the community advisory committee held conference calls and regularly scheduled meetings. The University researchers had limited data sources and did not have any experience working with tribal communities. The University team managed to get approval to use tribal specific data from AASTEC and cited many of the community specific data in their final report. Issues arose for me as I began reviewing the final reports and presentations being assembled for the funding requirements. Although community members were involved with the HIA from start to finish, not one community

member was listed among the slew of university authors. Another point of contention is the final report quotes data and study results specific to the Tribe. Community and participant privacy come into question as high rates of poverty, asthma, and alcohol use are cited.

Another issue I came across in review of the final report and presentations was the visual images of Village housing maps, which included sensitive information about the physical locality, mold status and overall condition of every single home within a defined boundary. I felt it was a breach of privacy and questioned the need for heightened security. I feel it is against the best interest of the community and tribal members to have visual images such as aerial maps and views of the village including actual images of Kivas and layout of the community available for anyone to see.

When the University researcher was confronted with the concerns and asked if the research team had gotten approvals from tribal leadership to release the report, the university researcher stated that perhaps permissions and approvals had been obtained in the beginning of the research collaboration months ago. As of December 2016, no proper approvals have been obtained from tribal leadership as to the appropriateness of identifying the Tribe along with sharing of tribal and community specific data presented in publicly available reports and presentations.

2. W.K. *Kellogg Foundation and University of New Mexico*

The second research project involved a data gathering project being funded by W.K. Kellogg Foundation in collaboration with the University of New Mexico Health Sciences Department, Division of Community and Behavioral Sciences. A whole years'

worth of meetings and work had occurred before any attempt had been made to contact tribal leadership for proper approvals. This project had project staff from several entities meeting regularly and compiling a data base of publicly available health, language, census, education and other data about *Pueblo* X and its tribal members. The information gathered was then imported into a software called *Tableau* to promote the utility of the software and potential use to tribes. Very detailed and in-depth information and data specific to the Pueblo was put into *Tableau* software and reports were shared at University meetings without the tribe's consent or approval. A tribal council resolution or tribal leadership approval had not been obtained before researchers started compiling data. There was no discussion with the tribe to see if this was something the tribe would want to engage in or approve of. When researchers were approached to discuss the sensitivity of the data and lack of proper permission to collect this data, they responded by saying that the data is publicly available and that anyone could compile this data if they wanted to. The researchers were attempting to do a service for the community in compiling the data for potential use in grant proposals without asking prior permissions to do this on behalf of the tribe. Once confronted about the inappropriateness of their actions without prior Governor's approval, the university research team started the process of reaching out to the tribal leaders to get approvals after the data had already been compiled.

Problem Statement

When outside researchers gather data and access tribal specific information, there is a need to have clear research guidelines that are established by the community and

describe culturally appropriate ways to engage in research with tribal communities, including development of topics of inquiry, data ownership, management and storage, and methods for obtaining approvals for the dissemination of study results. Without formally written and approved research guidelines, the privacy of our community and sensitive information about our tribe and tribal members could be jeopardized.

Research projects conducted by outside entities involving the Pueblos do not have concrete guidelines to follow in an effort to promote transparency and human protections. Information shared in the report drafted by the University of Virginia HIA team highlight the need for oversight of research activities by tribal leadership or its designated authority. Establishment of research guidelines would promote the protection and security of community members while maintaining the integrity of the data that is being collected and reported on.

Tribal leadership engagement in this conversation is crucial and thus they are the main audience for this paper. There is currently a long standing, unwritten traditional protocol in place for anyone wanting to engage in any business or activity with the Pueblo community. The process usually begins with an outreach to the Governor and Lt. Governor of the tribe to schedule an in-person meeting at the Governor's chambers located in the tribal offices. The final approval to any question having impact on the larger tribal community requires tribal council approval along with the Governors approvals. Community members and people familiar with the community may be aware of this traditional protocol. This knowledge however, may not be readily available to outside entities and persons or organizations not familiar with Pueblo protocols.

The issue highlighted in this policy paper can occur when local and traditional protocols are not known or followed by researchers or outside entities engaged within the community. Researchers who are collecting and gathering data on a Pueblo and its tribal members have no written guidelines to follow for data collection, reporting or other data dissemination purposes. Given the degree of differences in cultural considerations, a researcher from the university might not have the knowledge of local protocols that would constitute ethical engagement with tribal stakeholders. Oftentimes, outside researchers may gain access to sensitive information through key informants and even through the public domain. More and more, local tribal nations such as Hopi Nation, Navajo Nation, and others across the Southwest are convening Institutional Review Boards to regulate research occurring with their communities and with their tribal members.

Policy Alternatives

The Community-Based Participatory Research (CBPR) approach has been highlighted as a socially just approach to research engagement with all types of communities, including Native American communities. Core principles of CBPR involve having the community involved in the research process along with making a long-term commitment to sustainability, lasting longer than any one project period or funding cycle (Minkler & Wallerstein, 2008). Some researchers go far beyond having the community involved in the selection of the research question, involvement in the research design, and a say as to how the results will be disseminated. Dr. Nina Wallerstein, a professor at the

University of New Mexico Health Sciences Center, has scientifically studied this approach to research with tribal leaders and community members from Jemez Pueblo, and other tribes in New Mexico (N. Wallerstein, personal communication, May 16, 2014).

An overall adoption of the CBPR approach to research by Pueblo communities will begin to build a strong foundation of strengths-based efforts with tribal leadership oversight through every step of the research process. The following are examples of policies and practices in tribes or tribal serving institutions that can serve as a menu of potential policy options for Pueblo communities to consider.

1. The University of New Mexico Health Sciences Center (UNMHSC) Native American Alliance for Community Health and Wellness (NAACHW) is currently working on a research policy that uses a locally developed document of research guidelines titled "*Guiding Principles for Engaging in Research with Native American Communities"* (Straits, Bird, Tsinajinnie, Espinosa, Goodkind, et al. 2012). The document is co-authored by a Santo Domingo tribal member and is the foundation of a policy draft which aims to establish American Indian and Alaska Native research guidelines that promote equitable and respectful research relationships among tribal entities and the UNMHSC faculty and staff (J. Baca, personal communications, November 4, 2016). If approved, the policy would require all UNMHSC faculty and staff involved in research with tribes to read and be tested on core elements of the eleven guiding principles to receive certification to conduct scientific research at UNMHSC. Drafting policy that

requires educating researchers about the foundations of culturally competent and respectful research engagement with tribal communities is a step toward social justice in research and education.

The Hopi Tribe has a *Protocol for Research, Publication and Recordings: Motion, Visual, Sound, Multimedia and other Mechanical Devices* (Available at: http://www8.nau.edu/hcpo-p/ResProto.pdf) which is administered through the Hopi Cultural Preservation Office. The Policy aims to protect the rights and privacy to Hopi intellectual property. Because of continued abuse, misrepresentation and exploitation of the rights of Hopi people, it became necessary to establish guidelines to protect the rights of current and future generations of Hopi people (Lomawaima, 2000). The protocol requires researchers to submit a proposal that addresses tribal concerns, possible benefits to the tribe, tribal access to research data and results, and tribal share in publication (Lomawaima, 2000, p.11).

2. Navajo Nation has established their own *Research Review Board (RRB),* which establishes a culturally appropriate procedure for handling research engagement on the Navajo Nation as well as with any research involving Navajo Nation tribal members. A thorough review of the research proposal, design, risks, and benefits are considered before approval is given to for any research project to commence and this is all for the protection of the community and its tribal

members. The Navajo nation RRB has developed a "brother/sister relationship" and requires a Navajo student to be paired with the Principle Investigator of the research project to form community relationships and foster a co-learning and mutually beneficial environment (B. Pigman-Bicenti, personal communications, November 2014).

3. Arizona State University's American Indian Policy Institute (AIPI) recruits students from the tribes that contract with them to promote mutual financial and academic benefit. Students get to learn real-world, on the job experiences working with their tribe and outside institutions while being afforded the opportunity to earn academic credit for coursework. The AIPI considers the resulting opportunities to be a mutually beneficial endeavor and has followed their students throughout graduation and as they get hired in professional roles in their tribe's and out in the community.

4. Portland Area Indian Health Service Institutional Review Board: Guidelines for Researchers

   An example of self-determinism in research is that of the Portland Area Indian Health Board and their model of ethical research engagement with American Indian communities. The establishment of the Portland Area Indian Health Services Institutional Review Board was to give oversight to any research conducted within the Portland Area IHS facilities and local tribes. The IRB

reviews research involving data collected within their local IHS facilities or with research involving local tribal communities. A high standard of research education has been established within the PAIHB and their organization continues to be active in heath research projects such as the Garrett Lee Smith Suicide Prevention Grant administered through the Substance Abuse and Mental Health Services Administration (SAMHSA). The PAIHB IRB maintains oversight of research protections for youth and other community members involved in research through any of their partnering institutions.

5. The *Southwest Tribal Institutional Review Board (IRB),* provides services to tribes in NM, Colorado, & Texas, to provide supplemental review of research projects based on federal code & regulations specific to human subjects' protection. The Southwest Tribal IRB was established to protect the rights and welfare of people who participate in research activities. This does not replace local tribal review and approval but is meant to provide additional oversight and recommendation. Tribes are required to submit a tribal resolution indicating the approval and authorization of Southwest Tribal IRB services. Mescalero Apache and Laguna tribes have representatives from their community that sit on the Southwest Tribal IRB as research protocol reviews. The current coordinator for the Southwest Tribal IRB is from Santo Domingo Pueblo.

Policy Recommendations

All eleven participants interviewed for this study stated that their tribal community did NOT have research guidelines in place. There is a need for *focused discussion* among tribal leadership and their appointees to establish a strategic plan for creating guidelines for conducting research in Pueblo communities. Until tribal specific guidelines are established, it is recommended that the All Pueblo Council of Governors leadership discuss the potential to partner with the Southwest Tribal Institutional Review Board for research oversight in the interest of protecting the rights and privacy of Pueblo research participants.

I recommended that Pueblo communities begin to work on establishing tribal specific protocols that researchers must follow when conducting research within their tribal lands and jurisdictions. A document that was co-authored by Ms. Bird while working at the UNM Health Sciences Center titled, "*Guiding Principles for Engaging in Research with Native American Communities"* can be a framework to work from (Straits, Bird, Tsinajinnie, Espinosa, Goodkind & Spencer et. al. 2012). The vision of the *Guiding Principles* is to advance research towards more conscientious and socially just implementation and impact that will contribute to the realization of healthy, thriving Native American communities (Straits, Bird, Tsinajinnie, Espinosa, Goodkind & Spencer et. al. 2012). The intended use of the document is to: a) provide suggested principles to guide researchers, both non-Native and Native, when working with Native American peoples and their respective communities, b) provide written guidance on encountering and addressing challenges in research relationships and processes c) elicit thoughtful

discussion among researchers, and d) increase awareness of the responsibilities of researchers not only to the individuals participating in research but also to the communities they work with.

It is recommended that *consultation occur with the Southwest Tribal Institutional Review Board* to discuss local resources to assist in the development of tribal specific guidelines. In the meantime, some suggested applications of the *Guiding Principles* document that could be readily implemented are:

- Educate researchers who plan to work with Pueblo communities by requiring them to read the *Guiding Principles* document and support them in implementing the principles. Share the *Guiding Principles* document with collaborators and university partners to provide a rationale for community based and community informed research.
- Facilitate periodic and ongoing discussions with research team members to ensure cultural competence, and mutual benefit.
- Share in discussions with tribal leaders and community partners to build capacity and generate discussion of research collaborations.
- Use in co-development of project guidelines and expectations of each party involved with project proposals. Lay out expectations and requirements to work in a culturally sensitive, ethical and respectful manner.

  Use the *Guiding Principles* document in MOU's for research collaborations to ensure partners will abide by the principles.

Recommendations for Research

- Always get proper approval before conducting research at any Pueblo
- Consider the three C's: consultation, collaboration, coordination
- Make sure the research is going to benefit the people
- Do your research about the community before coming in or fully formulating the research design?
- "We have a private life that's different from the outside world. There are levels of confidentiality that we adhere to in the village and not everything is open to them." (Pueblo Leader, Personal communication, March 12, 2018).

Conclusion

Research Guidelines are Needed in Pueblo Communities. Pueblo leaders agreed that research should be controlled by Tribes. To get a more representation and a complete data set for this study, participation by all Pueblos is encouraged. It is advised to incorporate local protocols in research that takes place on Pueblo lands to increase cultural sensitivity and Pueblo leader engagement in the research process.

The heightened need for security and safe storage of protected data and information warrant the need for tribal leadership to have focused discussions on establishing research guidelines for their communities. In the age of electronic information, it can be easy to get left behind in the technology and forward moving systems. It is imperative that

Pueblo leaders take the time to step back and engage in a deep discussion of what types of data are being collected in our communities and in what ways the information is shared. To protect the integrity of our communities and sustain our people, Pueblo leaders and communities must join and take ownership in deciding their next moves in the realm of scientific research. It is recommended that this pilot study be replicated with all 19 Pueblos of New Mexico including Ysleta Del Sur in El Paso, Texas to get a baseline of information to use in creating guidelines for research with Pueblo communities.

Former Governor of Tesuque, Rick Vigil, states "The framework that you are creating now puts principles in place for us to integrate into the future to have protocols in place. With these protocols, it controls what research is going on and to be respectful to tribal governments." We have concluded the initial study with Pueblo leaders to gain a baseline understanding of their definitions and perceptions of research. Although this study has ended the work will not end here and now we have incredible ideas and suggestions of ways to move research forward and culturally appropriate and sensitive manner with Pueblo communities. This research can shed light on a model that can be developed with other native communities. We have begun to create a framework of guiding principles for tribes and researchers to use in the future. The work, the learning, the asking of the questions never end. We as Pueblo people are researchers and we can be diligent in our assessments when it comes to what is important, the people of our communities.

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APPENDIX A

2017 SOUTHERN PUEBLOS COUNCIL AGENDA REQUEST FORM

APPENDIX A

SOUTHERN PUEBLOS COUNCIL

Acoma - Cochiti - Isleta - Jemez - San Felipe - Sandia - Santa Ana - Santo Domingo - Zia - Ysleta del Sur

2017 Southern Pueblos Council Agenda Request Form

Date Submitted: 10/5/2017 Schedule Date Requested 10/12/17

Tribal or Organizational Affiliation: Kewa Pueblo

All items must be submitted seven (7) days or more prior to the next Southern Pueblos Council meeting. You must be present to answer questions on action items. Please attach all relevant documents and (12) copies to the Pueblo of Jemez Governor's Office, no later than 12:00 p.m. the day prior to the scheduled meeting date.

SUBMITTED BY: Doreen Bird Phone #:(505) XXX-XXXX

Tribe/Company/Organization: ASU

Address: PO Box 647

City: Santo Domingo State: NM

SUBJECT and DESCRIPTION OF PRESENTATION: (Please be specific)

Ms. Bird is a third year PhD student in ASU's Pueblo PhD Cohort. She would like to introduce her dissertation topic titled, "Pueblo Leader Definitions, Values, and Visions of Research in Pueblo Communities" to give an update on the status, request feedback as to the appropriateness of the topic and to garner support for her research.

WILL YOU REQUIRE A RESOLUTION? YES NO X
ACTION or OUTCOME YOU WOULD LIKE: X NO ACTION

I would like the committee to give me their blessing and allow me to move forward with my research as soon as ASU institutional Review Board gives the OK to start conducting interviews of tribal leaders.

All requests for placement on the Agenda for the Southern Pueblos Governors Council must be pre-approved.

Reviewed by Officers:
Recommended Action

1._____
_____
Chairman Governor Joseph A. Toya, Pueblo of Jemez

2._____
_____
Vice-Chairman/Lt. Governor Jerome Lucero, Pueblo of Zia

3._____
_____
Secretary-Treasurer Governor Eugene Herrera, Pueblo of Cochiti

RECOMMENDATION BY OFFICERS WHETHER TO PLACE ON AGENDA:

_____Approve _____Deny _____ Schedule for a later date _____No Recommendation

APPENDIX B

ALL PUEBLO COUNCIL OF GOVERNORS DRAFT MEETING AGENDA FOR NOVEMBER 16, 2017

APPENDIX B

ALL PUEBLO COUNCIL OF GOVERNORS

Officers:
E. Paul Torres, Chairman
Governor Val Panteah, Sr., Vice Chair
Governor J. Michael Chavarria, Secretary

Acoma
Cochiti
Isleta
Jemez
Laguna
Nambe
Ohkay Owingeh
Picuris
Pojoaque
Sandia
San Felipe
San Ildefonso
Santa Ana
Santa Clara
Santo Domingo
Taos
Tesuque
Ysleta Del Sur
Zia
Zuni

DRAFT APCG Meeting Agenda

November 16 , *2017, 9:00 a.m. –12:00* noon
Parish Religious Education Building
Pueblo of Isleta, New Mexico

I. CALL TO ORDER — APCG Chairman E. Paul

II. INVOCATION — TBD

III. ROLL CALL — Governor J. Michael Chavarria, APCG

IV. APPROVAL OF MINUTES — APCG Governors

V. APPROVAL OF AGENDA — APCG Governors

VI. WELCOME
Governor J. Robert Benavides, Pueblo of Isleta

VII. ACTION ITEMS
APCG Resolution 2017-16 SOUTHWEST REGION TRIBAL INTERIOR BUDGET REPRESENTATIVE

VIII. INFORMATIONAL PRESENTATIONS
Textiles and SAR, Brian Vallo
AmeriHealth Caritas, Joseph Ray
Dissertation Topic "Pueblo Leader Definitions, Values and Visions of Research In Pueblo Communities" Doreen Bird
Crow Canyon Archeological Center, Sharon Milholland
Petroglyph National Monument Management Plan, Dennis.Vasquez
Economic Impact Assessment, Gwen Aldrich and Jeffrey Mitchell

APPENDIX C

INTERVIEW QUESTIONS

APPENDIX C

How do current Pueblo leaders define, value, practice and envision research in Pueblo Communities? *ID#*_____

Research Interview Questions

1) In your own words, can you tell me what the word "*research"* means to you?
2) Is the idea of research something that is only done by outsiders, academics or "scientists"?
3) Are there Pueblo processes or activities that you would consider being research?
4) How are they similar to or different from "scientific" or academic research?
5) Do you think there are opportunities for collaboration between outsiders and community researchers? Do you know of any community members doing research in or outside of your community?
6) What kind of research do you see taking place in your Pueblo community, either by outside scholars or community members?
7) What do you think outside researchers need to know before conducting research in your Pueblo community?
8) What do you think Native researchers need to know before conducting research in Pueblo communities?
9) What is the most important thing any researcher should think about before doing research in Pueblo communities?
10) Do you see benefits from research for your Pueblo community? If yes, what are some examples? If no, ask why they feel that way.
11) Do you see negative impacts from research for your Pueblo community? If yes, what are some examples? If no, ask why they feel that way.
12) What do you see as important future research topics for Pueblo communities?
13) Does your Pueblo community have established research guidelines? If so, who makes sure those guidelines are being followed? If not, who would be appropriate to monitor research guidelines are being followed?
14) Who approves research activities in your Pueblo community? Do you have ideas or suggestions for how this process might be improved?
15) Who oversees research activities in your Pueblo community? Do you have ideas or suggestions for how this process might be improved?
16) Do you think it would be important to have an office of research for all or each Pueblo community?
17) What do you see as the top priorities for future research in Pueblo communities?
18) What do you see are the biggest barriers to doing research in Pueblo communities? What are some suggestions to overcoming those barriers?
19) Do you think research should be controlled by Tribes?
20) What's the best way to begin a research partnership?
21) How often is appropriate for receiving updates on research projects in your community?
22) Is there anything else you would like to say about this topic?

Lastly, I would like to know:

What do you love about your Pueblo community?

Would you like to draw a quick picture or symbol of what you love?

Thank you so much for taking this time to share your knowledge. The information from this study will be shared with you and other tribal leaders and community members. Please let me know if it is ok to contact you in the future to clarify responses if needed. May you be blessed in all that you do for Pueblo communities!

APPENDIX D

APPROVED RESEARCH PROTOCOL

APPENDIX D

ASU Knowledge Enterprise Development
ARIZONA STATE UNIVERSITY

SOCIAL BEHAVIORAL INSTRUCTIONS AND TEMPLATE		
NUMBER	DATE	PAGE
HRP-503a	4/27/2018	114 of 131

Instructions and Notes:

- Depending on the nature of what you are doing, some sections may not be applicable to your research. If so, mark as "NA".
- When you write a protocol, keep an electronic copy. You will need a copy if it is necessary to make changes.

1 Protocol Title

Include the full protocol title: Pueblo Leader Definitions, Values, and Visions of Research in Pueblo Communities

2 Background and Objectives

Provide the scientific or scholarly background for, rationale for, and significance of the research based on the existing literature and how will it add to existing knowledge.

- Describe the purpose of the study.
- Describe any relevant preliminary data or case studies.
- Describe any past studies that are in conjunction to this study.

The purpose of this study is to gain an understanding of tribal leader perspectives on research in Pueblo communities. Much of what has been written in the scientific literature about the history of research in American Indian and Alaska Native (AI/AN) communities has discussed issues of power imbalances, negative stigmatization of AI/AN communities, and a feeling of mistrust in the research process (Smith, 1999). Yet, there is not much in the literature specific to Pueblo leaders' perceptions of research. This study will reflect an emergent, qualitative design that will employ Indigenous methodologies and face-to-face interviews. The central research question is: How do Pueblo leaders define, value, practice, and envision research? The main objective of this study is to gain a foundational understanding of Pueblo leaders' current perceptions of research in order to inform the development of research policies and procedures in Pueblo communities.

3 Data Use

Describe how the data will be used. Examples include:

- Dissertation, Thesis, Undergraduate honors project
- Publication/journal article, conferences/presentations
- Results released to agency or organization
- Results released to participants/parents
- Results released to employer or school
- Other (describe)

Data gathered through this study will be used for the construction of a dissertation in Justice & Social Inquiry, School of Social Transformation at ASU. Data and findings will be used for the publication of articles, book chapters, and presentations at conferences. Cultural protocols of the New Mexico Pueblo (Native American) communities whose leaders participate in the study will be followed in garnering approvals for the dissemination of study results. Results of the study will be shared with the collaborating partners and research participants. An oral community presentation will be given to the collaborating agencies.

4 Inclusion and Exclusion Criteria

Describe the criteria that define who will be included or excluded in your final study sample. If you are conducting data analysis only describe what is included in the dataset you propose to use.
Indicate specifically whether you will target or exclude each of the following special populations:

- Minors (individuals who are under the age of 18)
- Adults who are unable to consent
- Pregnant women
- Prisoners
- Native Americans
- Undocumented individuals

Inclusion criteria will be: Native American Tribal leaders from any of the 19 Southwest Pueblo communities 18 years of age and older who are well established in their Pueblo communities (see Letters of Support from Santo Domingo Pueblo Governor and Albuquerque Area Southwest Tribal Epidemiology Center). Exclusion criteria will include minors, adults who are unable to consent, and Prisoners.

5 Number of Participants

Indicate the total number of participants to be recruited and enrolled*:* A minimum of 10 participants and a maximum of 20 participants will be enrolled.

6 Recruitment Methods

- Describe who will be doing the recruitment of participants.
- Describe when, where, and how potential participants will be identified and recruited.
- Describe and attach materials that will be used to recruit participants (attach documents or recruitment script with the application).

The student researcher, Doreen Bird, will do the recruitment by providing a face-to-face presentation of the study for the collaborating agencies when Pueblo leaders will be given an opportunity to sign up for the study. Interested tribal leaders' names and contact information will be gathered on a hard copy sign-up sheet provided at the time of the presentation. Follow up contact will be made based on the information provided on the sign-up sheet that will ask for the preferred method of follow up with participants. The researcher will follow up individually with tribal leaders until the minimum number of participants is reached. If the number of required participants is not reached through the face-to-face method, an electronic email will be sent out to recruit participants until the minimum number is reached.

7 Procedures Involved

Describe all research procedures being performed, who will facilitate the procedures, and when they will be performed. Describe procedures including:

- The duration of time participants will spend in each research activity.
- The period or span of time for the collection of data, and any long term follow up.
- Surveys or questionnaires that will be administered (Attach all surveys, interview questions, scripts, data collection forms, and instructions for participants to the online application).
- Interventions and sessions (Attach supplemental materials to the online application).
- Lab procedures and tests and related instructions to participants.
- Video or audio recordings of participants.
- Previously collected data sets that that will be analyzed and identify the data source (Attach data use agreement(s) to the online application).

This research follows an emergent design which aims to collect narratives from Pueblo leaders by employing semi-formal interviews. One or two audio recorded interviews will be conducted with each participant lasting 45 minutes to 1 ½ hours at a location agreed upon by the participant and researcher. If invited to an event or meeting where research in Pueblo communities will be discussed, observation methods will be employed ranging from ½ to a full day recorded through field notes. The time frame of this study will range from April 1, 2017 to April 30, 2018.

8 Compensation or Credit

- **Describe the amount and timing of any compensation or credit to participants.**
- **Identify the source of the funds to compensate participants**
- **Justify that the amount given to participants is reasonable.**
- **If participants are receiving course credit for participating in research, alternative assignments need to be put in place to avoid coercion.**

There will be no compensation given to participants of this research.

9 Risk to Participants

List the reasonably foreseeable risks, discomforts, or inconveniences related to participation in the research. Consider physical, psychological, social, legal, and economic risks.

There will be minimal risk to participants of this study, which is similar to what someone would encounter in regular daily conversations.

10 Potential Benefits to Participants

Realistically describe the potential benefits that individual participants may experience from taking part in the research. Indicate if there is no direct benefit. Do **not** include benefits to society or others.

There is no direct benefit to research participants of this study other than having a space for their voice to be heard.

11 Privacy and Confidentiality

Describe the steps that will be taken to protect subjects' privacy interests. "Privacy interest" refers to a person's desire to place limits on with whom they interact or to whom they provide personal information. Click here for additional guidance on ASU Data Storage Guidelines.

Describe the following measures to ensure the confidentiality of data:

- Who will have access to the data?
- Where and how data will be stored (e.g. ASU secure server, ASU cloud storage, filing cabinets, etc.)?
- How long the data will be stored?
- Describe the steps that will be taken to secure the data during storage, use, and transmission. (e.g., training, authorization of access, password protection, encryption, physical controls, certificates of confidentiality, and separation of identifiers and data, etc.).
- If applicable, how will audio or video recordings will be managed and secured. Add the duration of time these recordings will be kept.
- If applicable, how will the consent, assent, and/or parental permission forms be secured. These forms should separate from the rest of the study data. Add the duration of time these forms will be kept.
- If applicable, describe how data will be linked or tracked (e.g. masterlist, contact list, reproducible participant ID, randomized ID, etc.).

If your study has previously collected data sets, describe who will be responsible for data security and monitoring.

Participants will be given the option to remain anonymous or to have their identity known. In cases where a participant wishes to remain anonymous, pseudonyms will be used in any reports or presentations describing this project or interview response.

Names and contact information (email address or phone number) must be collected to schedule interviews. Any hard copies of recruitment sheets, consent forms, and audio recording will be stored in a locked, fire resistant filing cabinet. Only the researcher will have access to the data which will be stored on password protected and encrypted laptops. Participants will be assigned random study codes or project IDs so that personally-identifying information (i.e., names and contact information) are not directly linked to interview recordings, transcripts, and other project materials. Study codes will be kept in a separate location from the consent forms and audio recordings to protect confidentiality of participants.

No identifying information will be included with interview recordings or transcripts. Upon completion of the final interview all documents containing personal identifiers will be destroyed.

12 Consent Process

Describe the process and procedures process you will use to obtain consent. Include a description of:

- Who will be responsible for consenting participants?
- Where will the consent process take place?
- How will consent be obtained?
- If participants who do not speak English will be enrolled, describe the process to ensure that the oral and/or written information provided to those participants will be in that language. Indicate the language that will be used by those obtaining consent. Translated consent forms should be submitted after the English is approved.

Free, prior, informed, consent will be obtained by Doreen Bird at a location agreed upon and selected by the participant. All participants for this study speak English. The consent process will take place prior to commencement of the initial interview. The researcher will explain the purpose, risks, and benefits of the study and inform the participant that study participation is completely voluntary and without compensation. Signed consent forms will be collected at the time of the initial interview.

13 Training

Provide the date(s) the members of the research team have completed the CITI training for human participants. This training must be taken within the last 4 years. Additional information can be found at: Training.

CITI Training was completed by Doreen Bird on 03-17-2016

APPENDIX E

STUDY CONSENT FORM

APPENDIX E

Consent Form

STUDY TITLE: Pueblo Leader Definitions, Values, and Visions of Research in Pueblo Communities

Greetings, I am a graduate student in the School of Social Transformation at Arizona State University. I am conducting a research study to investigate Pueblo leader definitions, values and visions of research in Pueblo communities.

I am inviting you to participate in a research study to gain information on Pueblo leader perspectives on research in Pueblo communities. Participation will involve an audio-recorded, face-to-face or phone interview, which will take approximately 45 minutes to 2 hours to complete. You have the right not to answer any question, and to stop participation at any time.

Your participation in this study is voluntary. If you choose not to participate or withdraw from the study at any time, there will be no penalty, and you are free to end the interview at any time. All research participants must be 18 years of age at the time of the interview date.

There is no direct benefit to your research participation other than having a space for your voice to be heard. Although there is no personal benefit to you, there may be possible benefits of your participation for overall Pueblo communities. There are no foreseeable risks or discomforts to your participation.

Any hard copies of recruitment sheets, consent forms, and audio recording will be stored in a locked, fire resistant filing cabinet. Only the researcher will have access to the data, which will be stored on, password protected and encrypted laptops. Participants will be assigned random study codes or project IDs so that personally identifying information (i.e., names and contact information) cannot be linked to interview recordings, transcripts, and other project materials.

No identifying information will be included with the interview recordings or transcripts. Upon completion of the final interview, all documents containing personal identifiers will be destroyed. You will have the option to remain anonymous. The results of this study may be used in reports, presentations, or publications but your name will not be used unless permission is given and indicated on this form.

I would like to audio record this interview. The interview will not be recorded without your permission. Please let me know if you do not want the interview to be recorded; you also can change your mind after the interview starts, just let me know.

If you have any questions concerning the research study, please contact the research team: Committee Co-Chairs: Drs. Bryan Brayboy, Bryan.Brayboy@asu.edu; and Mary Fonow, MaryMargaret.Fonow@asu.edu, or the student researcher, Doreen Bird,

dbird1@asu.edu or at (480) 965-7682. If you have any questions about your rights as a participant in this research, or if you feel you have been placed at risk, you can contact the Chair of the Human Subjects Institutional Review Board, through the ASU Office of Research Integrity and Assurance, at (480) 965-6788.

By signing below you are agreeing to participate in the study.

Name: _____

Signature:_____
Date:_____

Would you like your real name used in any resulting publications?
Check One : _____ Yes _____ No Researcher Initials:_____