ABSTRACT: This article discusses research-oriented responsibilities of the Zuni governor and tribal council to the Zuni people. To reduce potential negative effects and to enhance the lifestyle of the Zuni, these bodies screen and review research in an effort to ascertain compliance with tribal law, to be culturally respectful, and to determine what, if any, beneficial effects the research will have for the Zuni people. As a result, studies concerning high prevalence diseases, such as diabetes, are given preference. These principles may apply to other American Indian and Alaskan native communities.


Since historic times, my people have had direct interaction with researchers. Our community members have experienced good and bad ethnographic, genetic, epidemiological, and behavioral research. For example, ethnographic researchers in the late 1800s wrote about Zuni, disclosing esoteric religious and spiritual practices for popular magazines like The New Yorker and Atlantic Monthly. Ironically, these researchers collected sacred paraphernalia, bribing destitute tribal members with money, thereby creating a new norm for the illegal selling of sacred items and creating a demand by outsiders for ethnographic materials. Consequently, our community was deluged with researchers such as Frank Hamilton Cushing, Matilda Cox-Stevenson, and Ruth Bunzel. Archaeologists also created similar norms and ransacked entire villages from pre-Spanish contact sites. Currently, the “New Age” movement has created demand for fetishes and crystals as symbols of cosmic energy and power. This demand for sacred animal effigies and crystals has triggered looting of sacred sites and religious shrines where fetishes, rocks, and crystals are placed or deposited.
In the early 1980s, a researcher collected samples of blood for diabetes research, never disclosing to our community what was done and what the results were. Other researchers conducted kidney biopsies on adults and children who did not fit the criteria for biopsies. In some instances, biopsies were performed against the advice of physicians. A large proportion of research and researchers have been dishonest and unscrupulous when working among our American Indian and Alaskan native (AI/AN) communities. Yet, we value research that yields benefits and scientific principles that allow revisions in standards of care or other valuable outcomes. Lately, important research projects led by principal investigators who personify honesty and ethical principles have balanced the negative view of research conducted in our communities.

This article discusses several themes and perspectives on research that attempt to capture our Zuni Indian tribe’s (Pueblo of Zuni) point of view and the relevance of research approved and accepted by our Zuni community. Similar principles may be applicable to other AI/AN and minority communities.

I. THE ROLE OF THE ZUNI TRIBAL GOVERNMENT

Our Zuni people rely on us, the Zuni Tribal Council, to guide, direct and mediate all facets of our Zuni Indian Nation. As in other AI/AN communities, our tribal council is entrusted with the protection and welfare of our people, resources, and lands. The Zuni tribal constitution directs the Zuni Tribal Council to provide safe harbor for strangers to our lands and in their interaction with our people. Researchers directly interact with our constituents; hence, our direct governmental role is to control and facilitate research on the Zuni Indian reservation.

II. TRIBAL PERSPECTIVE

The Zuni tribal government values research, but also understands the need to control and screen research with our people. First, research objectives and outcomes must have value to AI/AN nations. Second, research on high prevalence diseases such as diabetes, kidney disease, cystic fibrosis, and alcoholism has priority. Third, AI/AN communities have growing sophistication about genetic research and storage of genetic materials. Descriptive and epidemiological studies are not particularly useful anymore; rather, clinical studies and randomized clinical trials are more relevant since they will yield more tangible principles and beneficial outcomes for the Zuni. Studies that replicate results can be beneficial if they yield direct and practical outcomes.

III. TANGIBLE AND BENEFICIAL RESEARCH

Research in our communities must address directly critical questions. Research projects will not be approved until prior literature searches and clarifying questions are completed. Several research projects approved by tribal councils had glowing summaries of literature searches and magnificent questions that could be answered, and the prospect of enormous benefits for our people. Yet, when the funds, survey process, and data collection stopped, our tribe received worthless results and the
caveat that additional research was needed to discern dependent variables and define confounding variables in a longitudinal study.

Research proposals must state a fundamental outcome question before the Zuni will approve the research. AI/AN tribes consider longitudinal research an impractical, shotgun approach, especially with multiple data collection methods and multivariate analysis as the sole analytical process. We qualify this statement when a thorough analysis and thoughtful design considers the analytical shortcomings and when the statistical power is increased and considered in the outcomes. Too often, the Zuni have approved longitudinal research proposals with several research questions that yielded nothing but more questions. In these instances, the analysis and statistical methods were an afterthought by the research designers. Precious resources and potentially useful data are wasted.

In view of the prior research conducted on our people, we do not regard pure research as suitable for our tribe. Research that employs practical principles from prior epidemiological research to alleviate health conditions and diseases is more useful. Current epidemiological and cross-cultural studies can yield valuable data and principles that could clarify and consolidate the fundamental directions research should take. In short, pure scientific knowledge as the sole endeavor is no longer meaningful for our people.

IV. HIGH INCIDENCE AND PREVALENCE STUDIES

The practical and beneficial harnessing of research is paramount for the Zuni. Research studies should yield principles and outcomes that improve health conditions. For instance, diabetes is a costly epidemic. Therefore, the Zuni and three other southwest Indian tribes have joined the National Institutes of Health (NIH) Diabetes Prevention Program (DPP). This randomized clinical trial has three arms that could yield clinical principles on lifestyle or medication as the best diabetes prevention mechanism. We have given priority to this research, as well as a kidney disease study, due to the high incidence of non-diabetes-related kidney disease and the concomitant dialysis rates. We anticipate that epidemiological studies will direct greater prevention outcomes by comparing the intensive lifestyle-change arm with the drug arm.

Diabetes is extremely disruptive to our community in terms of lives lost, decline in the quality of life, and high dialysis rates. We have had prominent tribal members die due to complications. We have had an increase in heart disease from complications of kidney disease. The local Indian Health Service hospital has been extremely competent in daily management and prevention efforts against diabetes. Alcoholism is another priority health problem. Research on this disease is similar to diabetes, with other confounding variables and genetic determinants that prevent a single cure and a single prevention program objective. The symptoms and decline of health and quality of life are costly.

V. GENETIC RESEARCH AND BIOLOGICAL SPECIMENS

Most AI/AN tribes, including Zuni, consider any body part, blood or buccal scrape, as part and parcel of their being that should not be separated from the body.
They believe that the spirit may be damaged if parts are apart from the body for long periods of time or upon death. We also believe that one must be whole for the journeys in the afterlife. Hence, autopsies are to be avoided at all costs.

Most tribal members understand the need for biological specimen collection for health care. Hence, there is no conflict between religious beliefs and the needs of medicine. Most tribal members understand and condone blood tests or other health maintenance tests as part of their physician's health service. Research specimen collection without limits on storage, however, is not acceptable. Our people have taboos against storage and permanent usage of biological specimens.

VI. INTELLECTUAL AND PROPRIETARY RIGHTS OF DATA AND SPECIMENS

The position of the Zuni tribe on ownership of data and clinical results is twofold. First, as a sovereign AI/AN tribe, Zuni control and govern all aspects of tribal members' health, security, and welfare; therefore, the tribe owns the data. Second, we have first right of review for publications and presentations. We review results and manuscripts prior to publication or presentation. These requirements may seem daunting to researchers. However, compared to other institutional hurdles, our system is very open and flexible.

We rely on our Health Board as the tribal Institutional Review Board (IRB). For researchers who truly have meritorious scientific questions, our procedure will expedite implementation of the study. The Health Board acts as the primary reviewer of all research proposals. It recruits expert advisors from tribal staff and submits recommendations to the Tribal Council for approval or denial of research proposals. The Tribal Council reviews and acts on recommendations or asks for further clarification from the researchers as needed. Usually, a full onsite presentation is requested after preliminary approval is granted.

The tribe will also work with the National Indian Health Service's IRB to allow researchers to enter our land and work with our people. If federal funds or access to local Public Health Service hospital data is involved, we request the Indian Health Service IRB to conduct a courtesy review for research projects we approve on our reservation.

Health issues confronting our tribe lead us to give priority to research that may improve standards of care or enlighten practitioners. We seek ethical and legally minded researchers for research partnerships yielding benefits to both parties. We look at genetic research as involving the very core of our people. Biological specimens are part of us; therefore, taboos exist to guide how our people may participate. As governor and Tribal Council, we are shields for our people. We filter potentially negative effects and secure positive practices and processes. Research can be dangerous and divisive for our people, yet our task is to facilitate access to our people for beneficial research projects. We harness the intellectual property of our people to safeguard their future existence.