

## **Pueblo of Zuni, Perspective on Research in American Indian Communities**

### **1) The Role of the Zuni Tribal Government**

- a. Zuni Council “guide, direct and mediate all facets” of Zuni in addition to being “entrusted with the protection and welfare” of their people. A direct governmental role is ensued to control and facilitate research on the Zuni Indian reservation.

### **2) Tribal Perspective:**

- a. The Zuni Tribal Council are primarily interested in research where its objectives and outcomes have values and where research on “high prevalence diseases,” such as diabetes, kidney diseases, cystic fibrosis, and alcoholism are prioritized. In addition, clinical studies and randomized clinical trials with tangible principles and beneficial outcomes are preferred. Replicated studies yielding direct and practical outcomes are also favored.

### **3) Tangible and Beneficial Research:**

- a. Research in the Zuni community must directly address critical questions with literature review and clarification of the question(s), in addition, the research must state realistic outcomes pertaining to the research. The Zuni consider pure research and longitudinal research impractical with elements of a shotgun approach as impractical to the Zunis. The Zunis view previous epidemiological research that holds practical principles to help ease health conditions and diseases as being relevant and valued to the Zuni people.

### **4) High Incidence and Prevalence Studies:**

- a. Research that is practical and beneficial is desired should it produce improved health conditions results. These improved health conditions in high prevalence diseases are diabetes, kidney diseases, cystic fibrosis, and alcoholism are given priority due to their impacts on the community and cost of lives.

### **5) Genetic Research and Biological Specimens:**

- a. Zunis consider any body parts, blood, or buccal scrape as part of their bodies and should not be separated from the body. The body needs to be whole in order to make a proper journey, if not; the spirit may be damaged if parts are apart from the body. However, there is an understanding of the need for specimen for the concerns of healthcare and wellbeing of a tribal member superseding conflicts of religious beliefs and medicine. However specimen storage without limits is not acceptable due to taboos.

### **6) Intellectual and Proprietary Rights of Data and Specimens:**

- a. Since Zuni “controls and governs all aspects of tribal members’ health, security and welfare,” they own the data, in addition, they have first right of review for publications and presentations prior to such activities. The Zuni Health Board serves as the Institutional Review Board (IRB). The Board are the primary reviewer of all research proposals, provide approval or denial recommendations, and ask for further clarification from the researcher.