

# Report on Research Compliance Volume 19, Number 1. January 02, 2022

## Build Relationships, Respect Autonomy to Conduct Research Within Tribal Populations

---

By Jane Anderson

Researchers seeking to conduct studies involving American Indian and Alaska Native (AIAN) communities need to work closely with tribal communities and take into account their unique cultures and perspectives, experts said at a workshop sponsored by the HHS Office for Human Research Protections.<sup>[1]</sup>

As part of this process, in which it can take years to gain trust from tribal leaders, researchers need to become familiar with community norms, cultures and institutions and how they relate to the Belmont principles, and must respect rules that call for tribal authority over the research and ownership of data, the experts said at the virtual workshop held last year.

Most people are familiar with the Tuskegee study, which led to extreme distrust of medical research in the Black community, explained Spero Manson, distinguished professor of public health and psychiatry, Colorado Trust Chair in American Indian Health, and director of the Centers for American Indian & Alaska Native Health at the Colorado School of Public Health. Manson most recently also served on NIH's Advisory Committee to the Director. However, fewer people know that AIAN communities had similar experiences with medical research, Manson said.

For example, the results of the Barrow Alcohol Study, in which researchers examined substance abuse and suicide in Barrow, Alaska, were released to the press in January 1980 before they were briefed to the local community, stigmatizing the population and crippling the ability of the town to obtain financing to continue developing their local resources and facilities, he said.

In another example, the Havasupai Tribe agreed in 1989 to let researchers from Arizona State University draw and test their blood in an attempt to identify a cause for the elevated rate of diabetes found in that population, Manson said. However, lawsuits ensued alleging misuse of biospecimens and genetic information to move beyond the risk of diabetes to Alzheimer's disease, and even to use the biospecimens and genetic information to trace ancestral migration across the continent, he said.

### Important Roles for Local IRBs

A series of presidential executive orders that began during the Reagan administration set the tone for obligations and requirements between tribal governments and the U.S. government, Manson said. These executive orders, fueled in part by the consequences of the Barrow Alcohol Study and the dispute between Arizona State University and the Havasupai Tribe, led to the establishment of institutional review boards (IRBs) in many AIAN communities, he explained.

"It's important to note that these institutional review boards are not only chartered under the current obligations of the federal government in terms of protecting human subjects, but also we often serve a broader role, and that is to provide community review of the priority, the importance, the salience of the particular topics that investigators—often external to tribal communities—propose to undertake, and also are designed to ensure

---

that tribal communities have appropriate roles and partnerships in all aspects of this research,” Manson said.

There are numerous cultural differences between nontribal researchers and AIAN communities, Manson said. For example, in universities and the federal government, the objective is to govern or control individuals and groups, while in tribal communities, the objective is to manage interdependent relationships, he said. In universities and the federal government, competence stems from delegated authority and administrative license, and accountability is couched in terms of blameworthiness and liability. In tribal communities, authority is rooted in moral and social responsibility, and accountability is framed as obligation to and acceptance by others, he said.

Cultural differences also abound, Manson explained. While the nontribal world tends to be egocentric, prize privacy and anonymity, and emphasize majority opinion, tribal communities tend to be sociocentric; seek cooperation; deemphasize conflict; and stress mutuality, belonging and solidarity, he said.

Points of tension between nontribal researchers and tribal communities include review and approval of research, distribution of resources, manner of informed consent, nature and extent of accountability and control, data ownership and sharing, and requirements for continued collaboration, Manson said.

This document is only available to subscribers. Please log in or purchase access.

[Purchase](#) [Login](#)