

Guidance on Research with American Indian Communities

Research projects on tribal lands require special considerations beyond federal regulations and University policy. Developing meaningful and ethical research with American Indian communities requires that researchers commit to a sustained process of relationship building, cross-cultural learning and respect, and reciprocity. This is especially important given both the historical context of research in Native communities and the role of research and information in geopolitical and economic decision-making. Tribal governments are sovereign nations and therefore have the legal authority to regulate all activities conducted on their lands and with their citizens, including research.

Societal Benefit

One key principle to remember as you develop your research topic is that the *results of the study should* be beneficial to the tribe. Ensure that research findings are useful and accessible to participating communities by providing information that contributes to tribal-specific solutions, greater well-being, or positive policy impact.

Partnerships

Researchers are encouraged to reach out and develop relationships within the tribe/community as you develop your research proposal. Build relationships that are sincere, enduring and based on mutual trust and respect. The community partner will provide insight on how the tribe would view the research topic and methods, the benefits of the research, what may cause concerns, etc.

Permission and Letters of Support

Each nation has different procedures for approving external research. When a research activity will occur in a tribal community, approval for the activity by a tribal official is necessary. Each tribe determines for itself the tribal official who has the authority to approve activity on its land. Sometimes the tribe will have its own review board (e.g. the Navajo Nation Human Research Review Board); sometimes the authority is given to an individual or group (e.g. tribal leader or council).

Tribal authorities/review boards may require proof of IRB review prior to their approval. If this is the case, once approval is obtained from the Tribe, an amendment must then be submitted to the UNM IRB to add that site to the project, including any changes required by the approving authority (i.e. consent form changes). The approval process can take time and must be built into the timeline of the project.

Data Ownership and Study Results

Tribes have the right to ownership and control over research data collected in their communities and may choose to share or not share ownership of the data. Note that depending on the Tribe, some require that upon study completion the data collected from the study be relinquished to the Tribe for ownership. It is also important to provide findings back to community stakeholders on an on-going basis.

Navajo Nation Research Review Board

The Navajo Nation Human Research Review Board (NNHRRB) was established in March 1996 to ensure that research within the boundaries of the Navajo Nation is conducted in an ethical and culturally



sensitive manner. The NNHRRB provides oversight and guidance for research that is intended to benefit the Diné people. Any person interested in conducting human research must inform the NNHRRB of his/her intent by submitting a Letter of Intent and abstract. This will initiate the review process. If approved, once the research is completed, the NNHRRB must approve the Final Report and Dissemination Plan (which may include presentations to chapters, schools, health boards/facilities or tribal programs) prior to any sharing of study results.

Indian Health Service IRBs

All human participant research conducted in IHS facilities or with IHS staff or resources must be approved by an IHS Institutional Review Board (IRB). All proposed research must first obtain the formal, written approval of the appropriate Tribal government(s). This approval must be submitted with the original application to the IHS IRB. There are eleven IHS IRBs: National IHS IRB (Rockville, MD), Aberdeen Area IRB, Alaska Area, Bemidji Area, Billings Area, Nashville Area, Navajo Nation, Oklahoma Area, Phoenix Area, Portland Area, and Tucson Area.

Southwest Tribal IRB

The consortium tribes of Ramah Navajo, Tohajiilee Navajo, Mescalero Apache Tribe, Jicarilla Apache Nation, Ute Mountain Ute Tribe, and Southern Ute Tribe are served by the Southwest Tribal IRB. Laguna Pueblo submitted a resolution that authorizes the Southwest Tribal IRB to review their health-related research protocols. Other southwest tribes are indirectly served by the Southwest Tribal IRB if they collaborate with AASTEC or NARCH on projects that may result in research. The Southwest Tribal IRB is available to collaborate with southwest tribes to conduct a supplemental review of research projects based on federal code and regulations specific to human subjects' protection. The Southwest Tribal IRB does not supplant or replace local tribal review but is meant to provide additional insight and recommendation. It was determined that Tribes will be required to submit a resolution from their tribal government indicating the approval and authorization of Southwest Tribal IRB services.

Other Tribal IRBs

A number of tribal entities have formed their own IRBs under DHHS Title 45 of Federal Regulations Part 46 (Common Rule). Tribal IRBs currently include California Rural Indian Health Board IRB, Cherokee Nation IRB, Chickasaw Nation IRB, and Choctaw Nation IRB.

References and Resources:

Guiding Principles for Engaging in Research with Native American Communities: http://hsc.unm.edu/vision2020/common/docs/Guiding_Principles_Research_Native_Communities2012.p df

Navajo Nation IRB:

P.O. Box 1390 Window Rock, AZ 86515

Tel: 928-871-6929

Web: www.nnhrrb.navajo-nsn.gov

IRB Chair: Beverly Becenti-Pigman (bbp_pqih@yahoo.com) IRB Admin: Michael Winney (Michael.winney@nndoh.org)



Southwest Tribal IRB:

Albuquerque Area Indian Health Board

5015 Prospect Ave. NE Albuquerque, NM 87110

IRB Chair: Marvin Sarracino

IRB Coordinator: Rachell Tenorio (renorio@aaihb.org)

Tel: 505-962-2603

Web: www.mynarch.net

Email: SWTribalIRB@aaihb.org

Indian Health Service IRB (National):

5600 Fishers Lane, MS 09E10D Rockville, MD, 20857

Web: https://www.ihs.gov/dper/research/hsrp/

Email: irb@ihs.gov