

# UNIVERSITY OF ARIZONA GUIDELINES FOR RESEARCH AND INSTITUTIONAL ENGAGEMENT WITH NATIVE NATIONS

## INTRODUCTION

In February 2016, the Arizona Board of Regents (ABOR) adopted ABOR Tribal Consultation Policy 1-118 (ABOR 1-118 or the ABOR policy) which affirms ABOR's commitment to respectful government-to-government relationships with sovereign Native Nations. ABOR 1-118 functions as the highest level of authority, outlining ABOR's expectations and requirements when engaging with Native Nations by recognizing fundamental principles of sovereignty, consultation and respect. The University of Arizona guidelines were developed to support ABOR's policy, outlining institutional processes and procedures of respectful and ethical research and institutional engagements with Native Nations.

The ABOR policy notes that consultative expectations are "in support of and not intended to limit the already successful ongoing relationships between the Board of Regents, tribes, and universities." Further, these guidelines do not supplant tribal, federal, state, ABOR, and/or University of Arizona laws, regulations, and policies, or Institutional Review Board processes that also govern research and institutional engagement activities. However, as acknowledged in ABOR 1-118, laws that protect individual participants in research may not be sufficient to protect the interests of a sovereign tribe that could be affected by research. See "Note about Genetic Research" on page 2 and Section IV.E "Community Risk" for further discussion.

### I. RESEARCH OR INSTITUTIONAL ENGAGEMENT ACTIVITIES WHERE DOCUMENTATION OF CONSULTATION IS REQUIRED

Consultation and evidence of consultation is required for **any** of the following activities:

- The research or institutional engagement takes place in Indian Country, or Alaska Native homelands, and/or on land under the control or jurisdiction of a sovereign tribe.
- Human research is conducted in Indian Health Service (IHS) facilities or involving IHS staff or resources.<sup>1</sup>
- The research or institutional engagement involves participation by members of a sovereign tribe and may foreseeably result in research results with implications specific to a tribe or to individuals as members of the tribe.
- Any research or institutional engagement involving human remains, funerary objects, sacred objects, or objects of cultural patrimony that are subject to the Native American Graves Protection and Repatriation Act.
- The research involves human subjects, including genetic testing or testing of blood, tissue, or other biological materials if the individual's membership in or affiliation with a tribe is identified, and that is intended to or may foreseeably resulting conclusions or generalizations about a tribe or individuals as members of the tribe.

***A NOTE ABOUT GENETIC RESEARCH:*** *Unlike most other kinds of health information, genetic information applies to or is generalized beyond the individual. Genomic analysis can presumptively provide some information about a person's parents, siblings, children, and others. Some genetic research may produce discoveries that pertain to entire subpopulations, some of which correspond to racial or ethnic groups. Investigators must take steps to reduce the risk of stigmatization to groups with a shared genetic background even when risks to individuals are minimized through anonymization of data or specimens. The University recommends that **measures be taken to address group concerns including early and ongoing consultation and involving community members from potentially vulnerable groups in the planning and management of genetic research and in developing plans for the disclosure of research results.***

An enhanced informed consent clause may be required to advise participants/collaborators of the potential for elements of heightened risk to individuals and tribes when engaging in a genetic research study. For assistance in this regard, contact the University of Arizona Human Subjects Protection Program.

## **II. UNIVERSITY OF ARIZONA POLICY ON PROCEDURES AND RESPONSIBILITIES**

ABOR 1-118 requires that all human and non-human research projects including both unfunded and funded sponsored projects, University of Arizona Foundation initiatives, contracts, intra-university agreements, and other instruments related to tribal engagement must be supported by documented evidence of consultation and approval (ABOR 1-118 B (3)(b)). Consultation and agreements with federal, state, and/or pan-tribal agencies (e.g., Bureau of Indian Affairs, the Intertribal Council of Arizona, the Arizona Commission on Indian Affairs, the Tucson Indian Center, etc.) and committees (e.g., the President's Advisory Council on Native American Affairs, etc.) will be in coordination with, and not to the exclusion of, consultation with individual Native Nation governments and the requirement for evidence of tribal consultation and approval.

Documented evidence can include but is not limited to: letters or electronic communications of support or approval, memoranda of agreement or understanding, resolutions, contracts or other forms of agreement or evidence of consultation.

For:

**HUMAN RESEARCH:** A determination needs to be made whether the project is human research requiring IRB approval. Complete the "Determination of Human Research" form found on the [Human Subjects Protection Program](#) website. Should the project require Native nation approval, the Human Subjects Protection Program will require documented approval *before any research activity can begin.*



For:

**RESEARCH OR INSTITUTIONAL ENGAGEMENTS OTHER THAN HUMAN RESEARCH:** The principal investigator or project director is required to collect and retain documentation of consultation with approval or pending approval from the Native Nation. Please see Human Subjects Protection Program [Guidance and Procedures](#) for the University's data storage and retention policy. Authorizations (e.g., letters or electronic communications of support or approval, requests for assistance or engagement, memoranda of agreement or understanding, tribal resolutions, contracts, research or ethnographic permits, crossing permits, special use permits or other forms of agreement or evidence of consultation) are required prior to having access to Native land or property. The Native Peoples Technical Assistance Office (NPTAO) is available for assistance and support. These consultative documents are subject to audit on request.

### III. DEFINITIONS

The following definitions will aid in an understanding of concepts and principles related to respectful research and institutional engagements with Native Nations and Alaska Natives.

**Alaska Native(s):** Alaska Natives are indigenous peoples of Alaska, United States and include the Iñupiat, Yupik, Aleut, Eyak, Tlingit, Haida, Tsimshian peoples, and a number of Northern Athabascan culture. Alaska Natives are enrolled in federally recognized Alaska Natives tribal entities, who in turn belong to 13 Alaska Natives Regional Corporations who administer land and financial claims.

**Culture:** Culture and traditions vary greatly between Native Nations. Native peoples and communities also vary in adherence to their culture's origins and to Western cultural values and beliefs. For many Native people, spirituality and religion are generally perceived as an integral aspect of their culture. Spirituality also takes on many forms within Native American communities, from use of traditional Indigenous practices to Christian beliefs.

**Federally Recognized Tribe:** Federal recognition of a tribe means that the federal government recognizes tribal sovereign powers and the right to certain services from the United States that are primarily delivered through the Bureau of Indian Affairs and the Indian Health Service. Tribal recognition is a political classification, not a racial one, and is because tribes were self-governing in America before settlers came over from Europe. Federal recognition creates government-to-government relationships between the federal and tribal governments.

**Human Research:** Any research or clinical investigation that involves human subjects. Investigators conducting human research must satisfy the Department of Health and Human Services regulations (45



CFR Part 46) and Federal Drug Administration regulations (21 CFR Parts 50 and 56) regarding the protection of human subjects, as applicable.

**Indian Country:** a legal term, and except as otherwise provided in Sections 1154 and 1156, 18 US Code § 1151, the term Indian Country, as used in these guidelines, means

- a. All land within the limits of any Indian reservation under the jurisdiction of the United States Government, notwithstanding use of any patent, and including rights-of-way running through a reservation;
- b. All dependent Indian communities within the borders of the United States whether within the original or subsequently acquired territory thereof, and whether within or without the limits of the state; and
- c. All Indian allotments, the Indian title to which have not been extinguished, including rights-of-way running through same.

**Institutional Engagement(s):** This term refers to University of Arizona teaching, research, and extension/outreach/service.

**Research:** is the use of systematic methods to gather and analyze information for the purpose of proving or disproving a hypothesis. Research may also include evaluating concepts or practices, adding knowledge or insight to a particular discipline or field, or demonstrating or investigating theories, techniques or practices. A systematic investigation involves a prospective plan that incorporates data collection, either quantitative or qualitative, and data analysis to answer a question. For the purposes of these guidelines, research includes but is not limited to:

- Basic and clinical research.
- Behavioral studies.
- Anthropological and archaeological studies.
- Ethnographic studies.
- Community engaged participatory research.
- Practice-based research.
- Cultural or historical research.
- Feasibility and other studies designed to develop, test and evaluate basic data in all phases of environmental and public health.
- Research on plants, animals, water, land or weather.

**Sovereignty:** The inherent right of Native peoples to self-government, self-determination and self-education; governance of activities within Native lands, including research and institutional engagements.



**Traditional Intellectual Property:** The cultural information, knowledge, uses, and practices unique to a Native Nation's way of life. This property includes, but is not limited to: knowledge by remembered histories and traditions; details of cultural landscapes and particularly sites of cultural significance; records of contemporary events of historical and cultural significance; sacred property, including images, sounds, and knowledge, material, cultural or anything that is deemed sacred by the community; knowledge of systems of taxonomy of plants, animals, insects, and other beings; knowledge of current use, previous use, and/or potential use of land, water, plant and animal, fish, and insect species; knowledge of planting methods, ecosystem conservation, preparation, formulation, processing or storage of species; biogenetic resources that originate or originated on Native lands and territories; and cultural images, sound, crafts, art, dance, symbols, motifs, and names, practices and performances.

**Tribal Government:** The governing structure of a sovereign, federally recognized government of a Native Nation.

#### **IV. FUNDAMENTAL CONCEPTS**

The University of Arizona values its relationship with sovereign tribal governments throughout Arizona, across the country, and Indigenous Peoples around the world. The purpose of these guidelines is to assist university faculty, students and staff in implementing an informed and consultative approach when conducting research or institutional engagements with Native Nations/Alaska Natives on behalf of the University of Arizona.

An understanding and recognition of tribal sovereignty, early and continuous consultation, determination of formal and informal authority, demonstration that free, prior and informed consent has been obtained, and recognition of the potential for heightened community risk are fundamental concepts that must be applied to any and all research and institutional engagements with Native Nations.

Arizona is home to 22 Native Nation governments. Nationally, there are 567 federally recognized tribes. Each Native Nation has its own laws, codes, regulations, procedures and/or departmental guidelines governing activity occurring on tribal land. Research and institutional engagements with one Nation will not translate under the laws and procedures required by another Nation, thus highlighting the uniqueness of each Native Nation. These laws protect the tribes' communities and members while promoting the health, welfare and education of its citizens. Native Nations also have a unique political and legal status, which the University of Arizona recognizes, and respects.

##### **A. TRIBAL SOVEREIGNTY**



Sovereignty is the authority to self-govern. In the United States, Native Nations have inherent rights and a political relationship with the United States government, also interpreted to stem from the United States Constitution. Throughout United States history, hundreds of treaties, executive orders, and laws have created a fundamental contract between Native Nations and the United States affirming that Native Nations retain their inherent powers of self – government. Tribes continue to exist today as distinct sovereigns within the boundaries of the United States. This sovereign status is a defining feature of Native Nations and it differentiates them from other “communities” with whom the University of Arizona may engage. Therefore, any research or institutional engagement conducted on sovereign native land is governed under the authority of that individual Native Nation. Each Native Nation is the exclusive owner of all property on its lands and fully controls the disposition, development and use of its physical and intellectual property.

## **B. CONSULTATION**

Arizona Executive Order 2006 – 14, “Consultation and Cooperation with Arizona Tribes,” affirms the government-to-government relationship between the State of Arizona and each Native Nation located within the State of Arizona. ABOR 1 – 118 functions as the highest level of authority for Arizona’s three state universities, outlining ABOR’s expectations and requirements when engaging with Native Nations, by recognizing fundamental principles of sovereignty, consultation and respect. Consultation requires mutually agreed-upon respectful and timely communication with Native Nation governments in a cooperative process that intends to proceed toward consensus before a decision is made or an action is taken.

## **C. INFORMED CONSENT**

Documentation of Native Nation approval must demonstrate that free, prior, and informed consent for the research or institutional engagement has been obtained. The evidence of consent must be sufficient to demonstrate that the consent was provided prior to the research or institutional engagement and is based on adequate information regarding the intent of the research or institutional engagement and the ongoing use of resulting data.

## **D. AUTHORITY**

Each Native Nation will have a distinct procedure for review, approval and regulation of research or institutional engagement. These procedures will vary greatly depending on the Native Nation. Therefore, in addition to all federal laws and regulations pertaining to human research, it is the responsibility of the University of Arizona faculty, student, or professional to determine and abide by the Native Nation’s required procedure or protocol.



## **E. COMMUNITY RISK – ACADEMIC-TRIBAL COMMUNITY PARTNERSHIPS: Community Risk/Benefit**

ABOR 1 – 118 acknowledges, “Laws that protect individual participants in research may not be sufficient to protect the interests of a sovereign tribe that could be affected by research.” In the conduct of research and institutional engagements there may be elements of heightened risk to individual tribal members as well as to Native Nations, tribes and Indigenous communities that are not enumerated under the Common Rule (45 Code of Federal Regulations § 46).<sup>ii</sup>

Native Nations require thorough consultation and assessment of the benefits and risks of research and institutional engagement activities to community members. Risk may be legal, financial, social, physical, psychological, or spiritual in nature. Risks should be analyzed from the perspectives of both the individual and the group while remaining cognizant of the potential benefits that can also accrue to the group. Generally, Native Nations are concerned with the risks of exploitation, appropriation, and misrepresentation of traditional knowledge and intellectual property. If the research or institutional engagement is conducted on a reservation in a tribal community, keep in mind that tribal communities are typically small, making confidentiality problematic when members are either the subjects of a research protocol, or participating as members of the research team. Consideration of issues such as public policy impact, benefits and harms to communities and group consent may be necessary to address heightened risk.

## **V. RESEARCH AND INSTITUTIONAL ENGAGEMENT PRINCIPLES AND BEST PRACTICES**

Research, Discovery & Innovation encourages the campus community to consider these recommended best practice principles and questions when developing a research/institutional engagement protocol or plan where Native Nations and communities participate in the research or institutional collaboration:

### **A. COLLABORATION**

ABOR 1 – 118 II (A)(3) mandates that “universities and tribes will collaborate in the design of research [and institutional engagements] in which they jointly choose to participate.” Only Native Nations themselves can identify potential adverse outcomes resulting from research or institutional engagement, and they can do this only if there is an understanding of the assumptions and methods of the proposed research or institutional engagement. Individuals and communities who are the object of the research or institutional engagement should participate at all stages of the process – from initial



agenda setting to the development of policies based on the findings. Equal partnerships require collaboration in study design, data collection, interpretation and application. Past and ongoing abuses of tribal information highlight the need for formalized data-sharing agreements specifically crafted for the tribal –university context.

- Will the research or institutional engagement involve collaboration in the design, execution, and dissemination of results? What will the role of the collaborators be and have those roles been negotiated according to the concept of mutual respect?
- Are the Native Nation collaborators receiving acknowledgement as authors or co-authors of research publications?
- How will research results be communicated to research collaborators? Is there an end product or are there deliverables the Native Nation is specifically seeking that may have greater relevance than a written report?
- Does each aspect of research or institutional engagement such as informed consent, data collection, publication, or dissemination of results require Native language speakers?

#### **B. CULTURAL COMPETENCY**

- Are all aspects of the research or institutional engagement sensitive to the traditions, knowledge, and culture of the Native Nation?
- Are individual privacy and data confidentiality being respected? Native Nations reserve the right to exclude from access or publication any information concerning their culture, traditions, or spiritual beliefs. Does the research design or institutional engagement agreement recognize strictly limited or prohibited access to information such as places, names, certain types of knowledge, oral traditions, objects, or practices?

#### **C. DATA STORAGE AND SHARING**

- Will the material and data supplied by the Native Nation remain the exclusive property of the Native Nation? Will the data be shared with a third party? A separate formal archival or curation agreement, or material in data sharing agreement may be required for third-party participation.
- Some archived materials and data that were originally collected from Native Nations may be "held in trust" for the Native Nation. Ownership of these particular materials or information





may not have been relinquished and therefore remain the property of the Native Nation. Rules regarding ownership, control, access and use may have been formalized into an agreement between the Native Nation and the archival institution. Importantly, some archival materials already in the public domain may or may not be amenable to access, reproduction, display or publication. If relevant, how will this research or institutional engagement comply with the terms of the duration of the archival agreement?

- How will materials and data associated with the research or institutional engagement be accessed and used while meeting confidentiality requirements?

#### **D. COMPENSATION/BENEFITS/COSTS**

- Is the research or institutional engagement beneficial, community-based, community generated, culturally relevant and consistent with the priorities and concerns of the Native Nation?
- Has the researcher or university practitioner disclosed the benefits of the research or institutional engagement that will inure to the University of Arizona researcher or research team, and the University of Arizona?
- If relevant, has there been consideration of application of Native Nation hiring preference and compensation laws when filling paid positions?
- If compensation is appropriate, are Native Nation community collaborators being fairly compensated for expenses incurred in advising and assisting researchers or university practitioners?
- Have issues of additional on-site, in-kind costs been considered, including use of tribal facilities, personnel, and other associated meeting costs?

## **VI. RESOURCES**

The University of Arizona provides support and assistance to members of the University community who are planning engagements with Native Nations. The Assistant Vice President for Tribal Relations (AVPTR) is responsible for strengthening partnerships and advancing mutual goals between University of Arizona and Native Nations. The AVPTR is the key representative and liaison between tribal leaders and the University of Arizona.

The Office for Research, Discovery & Innovation (RDI) Native Peoples Technical Assistance Office (NPTAO) serves as the RDI liaison for Native Affairs. NPTAO provides research support, assistance and



training and education in Indigenous Law and governance through engagement and collaboration with Native Nations throughout Arizona. NPTAO has many resources available at <http://nptao.arizona.edu>.

Click on the Quick Links tab for background information on each of Arizona's 22 Native Nations. Included are the current leadership roster and government structure, tribal constitutions, tribal and federal laws that may pertain to research or institutional engagement, and community profiles for each tribe. The Research Support tab provides information on the most up-to-date policies and protocols for conducting research with Native Nations.

[The Human Subjects Protection Program](#) is available for consultation on whether a project is considered human research and the requirements for human research including development of appropriate consent forms.

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<sup>i</sup> Human research conducted in Indian Health Service facilities or involving Indian Health Service staff or resources must also be subject to review and approval by an Indian Health Service institutional review board – even if the protocol is already approved by a non-Indian Health Service institutional review board. Indian Health Service Institutional review boards require researchers to obtain formal, written consent from the appropriate tribal government(s).

<sup>ii</sup> See Rebecca Tsosie, "Cultural Challenges to Biotechnology: Native American Genetic Resources and the Concept of Cultural Harm," *Journal of Law Medicine & Ethics, Genetics and Group Rights*, (2007): 396-411; Debra Harry, "Indigenous Peoples and Gene Disputes," *Chicago-Ken Law Review* 84.1 (2008): 147-195; and Katherine Drabiak-Syed, "Lessons from Havasupai Tribe v. Arizona State University Board of Regents; Recognizing Group, Cultural and Dignitary Harms as Legitimate Risks Warranting Integration in to Research Practice," *Journal of Health & Biomedical Law VI* (2010): 175-225.

