

UNIVERSITY OF ARIZONA  
RESEARCH, DISCOVERY & INNOVATION

GUIDELINES FOR RESEARCH and INSTITUTIONAL  
ENGAGEMENT WITH NATIVE NATIONS (Draft 4.0/October 13, 2016)

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# 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 in support of 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 community, including its students, administrators, faculty and staff, is required to abide by and uphold all elements of the ABOR policy. 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.

These guidelines were developed in consultation and deliberation with faculty, staff and administrators representing colleges, departments, institutes, offices, and programs across the university. The ABOR policy notes that the 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 interests of a sovereign tribe that could be affected by research. See “Note about Genetic Research” on page 5 and Section IV E “Community Risk” for further discussion.

## I. 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 Athabaskan culture. Alaska Natives are enrolled in federally recognized Alaska Native tribal entities, who in turn belong to 13 Alaska Native 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 based in the fact that 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 & Human Services regulations (45 SCR 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 the term § 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 titles to which have not been extinguished, including rights-of-way running through same.

**Indian Tribe/Native Nation:** these terms refer to an American Indian or Alaska Native tribe, band, nation, Pueblo, village or community that the Secretary of Interior acknowledges to exist as an Indian tribe pursuant to the Federally Recognized Indian Tribe List Act of 1994, as amended.

**Institutional Engagements:** This term refers to University of Arizona teaching, research, and extension/outreach/service.

**Intellectual Property Rights:** a Native Nation is the exclusive owner of their distinctive bodies of traditional and cultural knowledge, and they have exclusive control over this knowledge regardless if the presentation is in a traditional form or if it has been recast as a product of research.

**Property Rights:** a Native Nation is the exclusive owner of the physical and intellectual property on their land, and fully controlled its disposition, development, and utilization.

**Research:** is the use of systematic methods to gather and analyze information for the purpose of proving or disproving a hypothesis, evaluating concepts or practices or otherwise adding to knowledge and insight in a particular discipline or field of knowledge or to demonstrate or investigate theories, techniques or practices. A systematic investigation is an activity that 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:

1. Basic and clinical research.
2. Behavioral studies.
3. Anthropological studies.

4. Community – engaged participatory research.
5. Practice-based research.
6. Cultural or historical research.
7. Feasibility and other studies designed to develop, test and evaluate basic data in all phases of environmental and public health.
8. Research on plants, animals, water, land or weather.

**Sovereignty:** The inherent right of Native people 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 the following: 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, insects species; knowledge of planting methods, ecosystem conservation, preparation, formulation, processing or storage of species, land, or in viral and; 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.

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

If your project involves any of the following activities, you must engage in consultation and evidence of consultation must be supported by documented evidence and approval.

- A. 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, or
- B. Human research is conducted in Indian Health Service (IHS) facilities or involving IHS staff or resources<sup>1</sup>, or

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<sup>1</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 and 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

- C. 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. Consideration must be given to whether the results of your activity will be distributed widely or may impact the way in which the public views a specific Native Nation, group, or tribal members, or reflect on a specific tribe's culture, health issues, history, or religion.
- D. The research targets Native Americans for enrollment or participation, or
- E. 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, or
- F. 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 result in 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 about more than one person. Genomic analysis can presumptively provide information about a person's parents, siblings, children, and others. Some genetic research can produce discoveries about 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 must be taken to address group concerns including early and continuous 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.***

*Investigators preparing to conduct genetic research should tell potential subjects which entities and persons will have access to the data. This might include investigators from other institutions, corporate sponsors, and government agencies. If information obtained during research will be recorded in a subject's medical record, this should be disclosed. Subject should also be told of the risks of others having access to his or her genetic information. Research subjects should be told that there is a small risk of future re-identification of de-identified information or bio specimens. In general, the researcher should discuss the following information with prospective subjects during the consent process:*

- *The purpose of the research in lay language.*
- *How the specimens and the data will be stored and who will have access to them or the information they contain.*
- *If subjects will be re-contacted later with information about the study findings or their individual results.*
- *If the samples or genetic information have a code that can be linked to the identity of individual subjects. When a link to identifiers is retained, the samples/information is not anonymous.*

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institutional review boards require researchers to obtain formal, written consent from the appropriate tribal governments.

- *If the researchers will use specimens to develop commercial products or assays, and whether the subject will be able to share any financial gain from these products.*
- *Whether the researchers plan to conduct future testing of samples.*
- *If samples may be used for other research studies, including those that may have a different focus.*
- *If research results, including general results, personal results and incidental findings, will be returned to the subject.*
- *Whether the samples and related data including biometric information and medical history may be withdrawn from further use upon subject's withdrawal from the project or upon subject's death.*
- *Upon withdrawal from the project, describe the nature of disposal of samples and whether a blessing by tribal healer or medicine man will be provided.*

*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 engaged in a genetic research study. For assistance in this regard, contact the University of Arizona [Human Subjects Protection Program](#).*

### III. PROCEDURES AND RESPONSIBILITIES

ABOR 1-118 requires that all human and non-human research proposals, 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 (2)(b)). 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:

- A. HUMAN RESEARCH: Determine whether your project is human research requiring IRB approval. If so, submit all required documents to the [Human Subject Protection Program](#).

For:

- B. RESEARCH OR INSTITUTIONAL ENGAGEMENTS OTHER THAN HUMAN RESEARCH: If the proposed research project or institutional engagement does not require IRB approval, in compliance with the ABOR policy, the principal investigator or project director is required to collect and retain documentation of consultation with approval or pending approval from the Native Nation (ABOR 1-118 II (C)(2)). 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 consultation) are required prior to having access to Native land or property. When submitting a proposal through [Sponsored Projects Services](#), copies of these authorizations shall be submitted as a component of the research or institutional

engagement. For all other programs or projects, the principal investigator or project director is required to collect and retain documented evidence of consultation and project approval. These consultative documents are subject to compliance review on the request of the Native Peoples Technical Assistance Office.

## IV. FUNDAMENTAL CONCEPTS

The University of Arizona values its relationships 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 566 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 United States government also interpreted to stem from the U.S. Constitution. Throughout U.S. 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 an individual Native Nation; and 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 the resulting data.

Informed consent may be required from a single individual or office, or multiple sources such as individual project participants, families, clans, religious leaders, or the tribal government.

## **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 Engaged Research and Community Risk/Benefit Assessment**

ABOR 1 – 118, acknowledges that "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>2</sup> In community engaged research, risks should be analyzed from the perspectives of the both individual and the group while

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<sup>2</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-Kent 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 into Research Practice," *Journal of Health & Biomedical Law* VI (2010): 175-225



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-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. Native Nations require thorough consultation and assessment of the benefits and risks of research activities to community members. Risk may be legal, financial, social, physical, psychological, or spiritual in nature.

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

The following section provides recommended best-practice questions to consider with developing a research/institutional engagement plan where Native Nations participate in the research or institutional collaboration:

**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 publication. Past and ongoing abuses of tribal information underline the need for formalized data-sharing agreements specifically crafted for the tribal-university context.

- Will the research or institutional engagement involve collaboration in its design, execution, and dissemination? 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 acknowledgment 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 or application 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? If so, how will this need be met?

## **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, mythologies, or spiritual beliefs. Is there recognition of strictly – limited or prohibited access or information relative to this research such as places, names, certain types of knowledge, oral tradition, objects, or practices integrated into the research design?

## **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 and 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 reproduction, display or publication. If relevant, how will this research program or institutional engagement comply with the terms of the duration or archival agreement?
- How will materials and data associated with the research or institutional engagement be accessed and used while meeting confidentiality requirements?

## **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 engagement 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?

# RESOURCES

**The Assistant Vice President for Tribal Relations (AVPTR)** – the AVPTR is responsible for strengthening partnerships and advancing mutual goals between the University of Arizona and Native Nations. The AVPTR is the key representative and liaison between tribal leaders and the University of Arizona. Any concerns related to tribal consultation and University/Native Nation relations should be brought to the attention of the AVPTR who will coordinate with appropriate university personnel and use best efforts to work with the designated representatives of the Nation Nation(s) and other affected individuals to reach a mutually acceptable resolution.

**The Office for Research, Discovery & Innovation (RDI) [Native Peoples Technical Assistance Office \(NPTAO\)](#)** serves as the liaison for Native Affairs to the RDI. Through engagement and collaboration with Native Nations throughout Arizona, NPTAO provides research support, assistance and training and education in Indigenous law and governance.

NPTAO has worked with many Native nations across Arizona to obtain copies of the most up-to-date policies and protocols that control research processes and outline procedures for conducting research. See NPTAO's webpage under [Research Support](#) .

Additionally, NPTAO's [Tribal Community Profiles](#) provide a current leadership roster and government structure, and a limited census-based introduction to Arizona's Native Nations. The profiles also provide citations of sections within each tribe's constitution, and tribal and federal laws that may pertain to research or institutional engagement.

NPTAO's Research & Engagement in Indian Country database (REIC Database): visit the [REIC Database](#) to learn ways in which our faculty, students and staff are actively engaged in collaborative projects in Indian Country.

The [Human Subjects Protection Program](#) is the administrative and regulatory support program to the institutional Review Boards to maintain an ethical and compliant research program. An IRB must review all research and related activities involving human subjects at the University of Arizona.

[Sponsored Projects Services](#) assists the University of Arizona research community in its efforts to secure external funding by providing high quality administrative and financial services to ensure proper stewardship of those funds.