

## Proposed update to the Native nations module on the CITI exam

### RESEARCH IN INDIAN COUNTRY: RESPECTING THE CULTURAL INTEGRITY AND SOVEREIGNTY OF NATIVE NATIONS

*Federal and state governments recognize the inherent sovereignty of American Indian nations. This module has been designed to educate university faculty, students and staff on best practices when conducting research with Native nations and their citizens.*

**MODULE OBJECTIVES/GOALS:** To educate university researchers about:

1. Native American sovereignty and implications for research;
  2. Community-based participatory research;
  3. Risks, harms, and benefits from a tribal perspective; and
  4. Consultation and approval procedures
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#### **OBJECTIVE 1. Native American sovereignty and implications for research**

**Sovereignty** is the inherent right of a people to self-government, self-determination and self-education; including governance within their lands/territory.

In the United States, there are three types of sovereigns:

1. The U.S. Federal Government
2. Each of the 50 State Governments
3. Tribal Governments

Sovereignty is expressed:

- Internally: by governance over citizens & jurisdiction over lands;
- Externally: through government-to-government relations, such as federal-tribe treaties, state-tribe compacts or agreements, University-tribe Memoranda of Agreement.

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. This status is reserved only for tribes recognized by the federal government under a treaty or federal recognition process. Sovereign status is a defining feature of Native nations and it differentiates them from other communities with whom a university may engage. Therefore, any research conducted on sovereign native land is governed under the authority of that individual Native nation.

### **Sovereignty and Implications for Research and Best Practices**

- Any research or institutional engagement conducted on sovereign native land is governed under the authority of that individual Native nation.
- In the research design, understand that 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.
- Throughout the research process, understand that sovereign Native nations have the legal right to:
  - Approve or deny requests for research conducted with Native communities, including research on reservation lands and resources, and with residents.
  - Halt research activities without disclosing their reasons.
  - Decide whether the outcomes of research activities conducted within their jurisdiction will be disclosed/disseminated (or not) in oral or written form.
  - Negotiate exclusive or shared ownership of research data.
- Learn about and follow all local protocols to obtain research permission from authority designated by the Native nation's government.

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### **OBJECTIVE 2. Community-based, participatory research**

As stated in Objective 1, sovereign status is a defining feature of Native nations and it differentiates them from other communities with whom a university may engage. The implications of sovereignty point to a community-based, participatory research (CBPR) design as the most appropriate when working with Native nations.

CBPR is an approach to research where communities are treated as equal partners at all stages of a research project. Some of the key principles of CBPR include: collaborative partnership between the researcher and community; the research builds on the strengths and resources of the community; and the research provides an educational opportunity for both the researcher and the community. The goal is for the community/tribal leaders and researcher to have a collegial relationship that has the greatest likelihood of creating new knowledge that results in improved outcomes for Native Americans.

### **Guidelines for Community-Based Participatory Research: Best Practices**

- **Partnership:** Native community representatives should be consulted and involved in all phases of any research project, including the research design (aim/method), implementation of the methodology, data collection and analysis, review and interpretation of results, and dissemination of findings.
  - Determine whether you may need a Native speaker to be engaged in the proposed work. Using Native speakers in the research process may be crucial to fostering clear communication and overcoming barriers associated with language.
- **Cultural Sensitivity:** Familiarize yourself with the culture, history, and modern or current dynamics of the Native nation or community with whom you intend to work.
  - Learn about community strengths, assets, and challenges.
  - Understand the physical, educational, social and health service infrastructure of the Native nation.
- **Funding:** As a research partner, the community has the right to recompense of any expenses that occur in the research process. For example, compensation for time, expertise, meeting accommodations, transportation arrangements and/or reimbursement should be addressed in the research budget.
  - Hire local community members of the nation as part of the research team; pay comparable wages for comparable work, or compensate appropriately.
- **Benefit to the Community:** The goals of the researcher are secondary to the benefit of the research to the community.
- **Long Term Sustainability:** Researchers must be committed to continuing relationships, support, capacity-building, and sustainability beyond the life of the project.

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### **OBJECTIVE 3. Risks, harms, and benefits from a tribal perspective**

Native nations require thorough consultation and assessment of the benefits and risks of research and institutional engagement activities to community members. Risks should be analyzed from the perspectives of both the *individual* and the *group*. Risk may be legal, financial, social, physical, psychological, or spiritual.

Researchers and institutional IRB's may not be adequately prepared to know all potential risks to Native communities. Only Native nations themselves can identify potential adverse outcomes resulting from research, and they can do this only if there is an understanding of the assumptions and methods of the proposed research.

Generally, Native nations are concerned with the risks of exploitation, appropriation, and misrepresentation of traditional knowledge and intellectual property. Native nations have legal and moral interests in the collection, use, storage and potential future use of data collected within their jurisdiction. Using a community-based participatory research design (Objective 2) will minimize the potential for risks and harms to the community.

### **Risk, Harms, and Benefits: Best Practices**

- Use a community-based participatory research design.
- Be aware that some information may not be culturally appropriate to study including certain ceremonies, medicines, and spiritual practices.
- With regard to biospecimens, genetic studies of origins of the population are particularly problematic to Indigenous peoples.
- Familiarize yourself with prior research done in the community. In some cases, past researchers have done harm that has affected how the Native nation views research in their community.
- In the research design, recognize that some tribal communities are small, making confidentiality problematic when members are either the subjects of a research protocol, or participating as members of the research team.
- Group consent may be necessary to address heightened risk.
- Follow Native nation's research protocols and IRB guidelines for consent forms, maintaining confidentiality, public dissemination of research, and all research procedures.
- Secondary use of any data (including biological samples) or data use by a party not identified in the original consent forms will require new approval by original approving entities such as affected tribes, **even if data are de-identified**.
- During/after the research project, feedback sessions should be conducted with the community to ensure correct collection and interpretation of data and project evaluation.

#### **OBJECTIVE 4. Consultation and Approval Procedures**

There are 567 federally-recognized American Indian tribes/Alaska Native (AIAN) villages, and approximately 400 non-federally recognized tribes. Tribal nations are extremely diverse in terms of cultures, languages, lands, governance structures, economies, and decision-making authorities. It is imperative that the researcher determine the local procedures to obtain research permission from authority designated by the Native nation's government.

Researchers should also determine if their institution requires documented evidence of consultation and approval. Approval documents may include:

- A copy of the tribe's IRB approval and/or a tribe's resolution (collective consent) approving the research proposal.
- Documented approval by a tribe's governing authority for research that does not involve human subjects, e.g. investigation of environmental samples, geographic surveys, and ecological research.
- Letters or electronic communications of support or approval, resolutions, contracts, permits, Memorandum of Agreement (MOA), Memorandum of Understanding (MOU), or other forms of agreement.
- Human Subjects/IRB documents.
- Medical Research
  - May require national or area Indian Health Service IRB approval and HIPAA training if research involves the use of IHS medical records, personnel, or facilities.
  - Medical research additionally requires the Tribal Chair/President/Governor or designee signature on the Assurance of Compliance with DHHS regulations form.
- Data ownership and dissemination of findings agreements.

### Consultation: Best Practices

- 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. It is the responsibility of the faculty, student, or professional to determine and abide by the Native nation's required procedure or protocol.
- Communicate early, regularly, and in good faith with individual tribal governments regarding proposed research, initiatives, agreements, and policies that may have foreseeable implications for tribes and individuals as members of a tribe.
- Native community representatives should be informed and involved in all phases of the research project, including research design (aim/method), implementation of the methodology, data collection and analysis, review and interpretation of results, and dissemination of findings.
- All consultative documents should be retained according to your University's data storage and retention policy.

### Additional Resources:

Check to see if your institution requires documented evidence of consultation and approval. For example, see the Arizona Board of Regents Tribal Consultation Policy and related information on the Native Peoples Technical Assistance research support page:

<http://nptao.arizona.edu/research-support>.

For information on sovereignty and tribal governance, see the National Congress of American Indians page: <http://www.ncai.org/policy-issues/tribal-governance>.

For information on consultation and culturally respectful research, see "Walk Softly and Listen Carefully: Building Research Relationships with Tribal Communities" NCAI Policy Research Center and MSU Center for Native Health Partnerships (2012).

[http://www.ncai.org/resources/ncai\\_publications/walk-softly-and-listen-carefully-building-research-relationships-with-tribal-communities](http://www.ncai.org/resources/ncai_publications/walk-softly-and-listen-carefully-building-research-relationships-with-tribal-communities).

For information on Community-Based Participatory Research, see Arizona Biomedical Research Commission. 2006. "Community Participatory Research: Enhancing Partnerships with the Native American Community." <https://azdhs.gov/documents/biomedical/annual-reports/Enhancing%20Partnerships%20with%20Native%20American%20Communities%202006.pdf>.

For information on conducting health research, see Solomon, Teshia G., and Leslie L. Randall (eds.). 2014. Conducting Health Research with Native American Communities. Washington, D.C.: APHA Press.