

# How to Conduct Research in American Indian and Alaska Native Communities



The Partnership for Native  
American Cancer Prevention,  
U54CA143924

Hopi NARCH, S06GM128012

February 2019

Volume III, Issue II

## Contents

Sovereignty & Government	1
Cancer Health Disparities	2
Sensitivity & Responsibility	2
Tribal Research Checklist	3
Resources	4
References	4

## This document is a guide for researchers on:

- Tribal Sovereignty;
- American Indian/Alaska Native Cancer Health Disparities;
- Researcher Sensitivity and Responsibility;
- Research Checklist; and
- Additional Resources.

Respectful research is the first step to maximize benefits of research.

## Tribal Sovereignty

There are a total of 573 federally recognized American Indian and Alaska Native (AI/AN) tribes in the United States (US), 22 of them in Arizona. Each one of the federally recognized tribes are Sovereign nations. Hundreds of treaties, executive orders, and laws have been signed to promote federal “trust responsibility” between AI/AN tribes and the US government. This means that tribes have the authority to govern themselves within the borders of the US.

With sovereignty comes the establishment of tribal governments. Each tribal government has the power to determine their own governance structures, and to pass and enforce laws. These governments are essential, because they have the ability to protect each tribe’s cultures and traditions. When undertaking research in partnership with an AI/AN community, a researcher should identify whether the target population is located within reservation boundaries and what laws govern research activities.

*Research with AI/AN is not the same as working with other underserved, minority or rural populations.*

It is imperative that researchers follow appropriate reviews and approvals before engaging in research activities.

In this guide, we offer a brief outline of basic items needed to conduct respectful and transparent research in AI/AN communities and list resources for additional detail (pg. 4). This guide is part of a series that the University of Arizona NACP Outreach has created. The other guides in this series are focused on:

- How to Build and Sustain a Tribal IRB, Volume I
- How to Review Research to Benefit Tribal Communities, Volume II
- Guidelines for Researchers, Volume IV

These resources are intended to provide useful and pertinent information to tribes and researchers so that outcomes can benefit tribal members and tribal communities. These guidelines are written specifically for research that would involve people, usually called human subjects. Most of the procedures and policies contained within these guides are based on current federal regulations, called *Code of Federal Regulations* (CFR), 45 CFR 46, for *human subjects protection*.

**Suggested Citation:** Gachupin FC, Molina F. How to Conduct Research in American Indian and Alaska Native Communities, VIII(1). Tucson, Arizona: University of Arizona, Department of Family and Community Medicine, College of Medicine, February 2019.

## American Indian/Alaska Native Cancer Health Disparities

According to the Indian Health Service (IHS), heart disease and cancer are the top two leading causes of death for AI/AN people (2018) (see Table 1). For cancer, AI/ANs are more likely to be diagnosed with advanced stage cancer compared to Whites (Hoffman et al., 2014) and have higher incidence of kidney cancer, uterine cancer, liver cancer, stomach cancer, gallbladder cancer, and myeloma than Whites (Batai et al., 2018). Related to these, AI/ANs experience varying degrees of issues related to access to health care, such as social structural, physical (transportation and physical distance), supportive, and cultural barriers (Itty et al., 2014). Research to understand the aforementioned is necessary, albeit on AI/AN terms.

**Table 1: Top Leading Causes of Death, AI/AN and US All Races Rates.**

2010 Census, age-adjusted mortality rates per 100,000 population.

Cause/Disease	AI/AN Rate 2009-2011	US All Races Rate 2010	AI/AN to U.S. All Races
Heart Disease	194.7	179.1	1.1
Cancer	178.4	172.8	1.0
Accidents	93.7	38.0	2.5
Diabetes	66.0	20.8	3.2
Respiratory Diseases	46.6	42.2	1.1

## Researcher Sensitivity and Responsibility

When working with tribes, researchers need to be familiar with and be sensitive to culture, traditions, and wishes and/or expectations of a given AI/AN community. Each tribe is unique and needs to be treated as an autonomous entity. Researchers are encouraged to establish participatory-type relationships with tribes and to have established these relationships prior to proposing research. For research focused on health, the partners should include the local community health department, and, as applicable the Health Board and/or the Indian Health Service. As the research protocol develops, tribal leadership should be included for review and approval. No research should begin until there is tribal clearance for the research to begin. Usually, the Institution-based review and approval process is also required. The timing of the processes are situation dependent. It is best to seek guidance from both the tribe and your institution.

*In working with tribes, the harms and benefits to be assessed are not necessarily the same as for other populations.*

It is imperative to understand the community's

- right to decline participation,
- self-assessment of harms and benefits,
- recognition of community-level harms and benefits,
- (dis)trust of research,
- experience(s) with stereotyping, discrimination or stigmatization,
- preference for ownership of data,
- request for ways to protect participant and tribal privacy, including how identification occurs in presentations or publications,
- preference for how to handle dissemination and implementation,
- preference for how to handle incidental findings,
- requirement to return results in a timely manner, and
- requirement for transparency, especially related to secondary uses of data.

## Steps for Conducting Research in Native Communities (NACE, n.d.)

- Get to know the tribal communities and establish relationships.
- Attend meetings and gatherings as a means to develop an appreciation for the history and culture of the tribe.
- Get a clear understanding of the historical trauma experienced by the tribe.
- Demonstrate respect for the community and its indigenous expertise through a Memorandum of Understanding.
- Hire members of the community to serve as consultants on various aspects of the research, such as data collection.
- A tribe's schedule for tribal ceremonies or tribal rituals should be accommodated.
- Appreciate the Native community's strengths, assets and challenges.
- Engage the community in the partnership with respect to tribal culture, language, and values.
- Be transparent.
- Undergo tribal and Institutional Review Board (IRB) review and approval.
- Respect the privacy of the tribal community.
- Employ blended research methods that include "indigenous ways of knowing."
- Limit scope of research to focus of questions only.
- Data sources, measures, and collection of information should be fully discussed with the tribe.
- Discuss intellectual and cultural property rights of the information including tribal data ownership.
- Keep the community fully informed as the study progresses and recognize contributions of community members.
- Study findings should be discussed with tribal leadership first.
- Have tribal leaders and key community members review all abstracts, reports and publications.
- Jointly determine how study results will be presented to the community and public.
- Consider sharing the results of the study in a public open community forum.
- Acknowledge and give credit to the community for the scientific results from the study.
- As applicable, consider including key community members as co-authors who participate in writing reports and publications.
- Discuss with the tribal community how they want to be recognized in publications and reports.
- Assist the tribal community in how to address findings of the research.
- Discuss with the tribe the storage and/or destruction of data, especially duration and access.
- Discuss with the tribe any next steps.

Tribal Priority

Capacity  
Building

Indigenous  
Ways of  
Knowing

Data  
Ownership

Credit to  
Community

Community  
Open  
Forum

## Resources

This guide provides information in brief and there are other resources available that provide more in-depth background and support (see following) including **Guidelines for Researchers, Volume IV** of this series.

The **University of Arizona Native Peoples Technical Assistance Office** provides research support; training and education; and technical assistance for tribal community development at: <https://nptao.arizona.edu/>

The **University of Arizona Subjects Protection Program** provides information on IRB Assurance and Registration, IRB Roster, Statements of Regulatory Adherence, and fee changes at: <https://rgw.arizona.edu/compliance/human-subjects-protection-program/about-the-irb>

The **Northern Arizona University Protocols for Native American Archival Materials** contains information about tribal sovereignty and how to conduct respectful research at: <https://www2.nau.edu/libnap-p/protocols.html>

The **Northern Arizona University Center for American Indian Resilience** has information about community assets, traditional knowledge, and cultural strategies at: <https://in.nau.edu/cair/>

The **National Congress of American Indians** has information about AI/AN codes, contracts, and IRBs at: <http://www.ncai.org/policy-research-center/initiatives/research-regulation>

The **Indian Health Service** provides additional resources regarding IRBs, grants, research studies, and programs at: <https://www.ihs.gov/dper/research/researchresources/>

The **Office for Human Research Protections** issues written guidance's, registers IRBs and FWAs, and provides information about the New Common Rule at: <http://www.hhs.gov/ohrp/>

**PRIM&R** is a leader for public responsibility in medicine and research providing educational programs and professional development opportunities that can be found at: <https://www.primr.org>

For further information about the **Belmont Report**, the **Nuremberg Code**, and **Helsinki**, please visit the OHRP website at: <https://www.hhs.gov/ohrp/international/ethical-codes-and-research-standards/index.html>

## References

- Batai K, Gachupin FC, Estrada AL, Garcia DO, Gomez J, Kittles RA (2018). Patterns of Cancer Related Health Disparities in Arizona. *Cancer Health Disparities* 2:e1-e20. Doi:10.9777/chd.2018.10019.
- Hoffman RM, Espey DK, Rhyne RL, Gonzales M, Rajput A, Mishra SI, Stone SN, Wiggins CL (2014). Colorectal cancer incidence and mortality disparities in New Mexico. *J Cancer Epidemiol* 2014, 8.
- Itty TL, Hodge FS, Martinez F. (2014). Shared and unshared barriers to cancer symptom management among urban and rural American Indians. *J Rural Health* 30, 206-213.
- Native American Center for Excellence, Substance Abuse Prevention, Steps for Conducting Research and Evaluation in Native Communities. Available at: <https://www.samhsa.gov/sites/default/files/nace-steps-conducting-research-evaluation-native-communities.pdf>. Accessed March 9, 2019.

### For more information, please contact:

**Francine Gachupin, PhD, MPH**

**Office: 520-621-5072**

**Email: [fcgachupin@email.arizona.edu](mailto:fcgachupin@email.arizona.edu)**

**University of Arizona**

**Department of Family and Community Medicine**

**PO Box 210491**

**655 N Alvernon Way, Suite 228**

**Tucson, AZ 85711**

**Fatima Molina, BSc.**

**Office: 520-621-5920**

**Email: [fatimamolina@email.arizona.edu](mailto:fatimamolina@email.arizona.edu)**



COLLEGE OF MEDICINE TUCSON

Family & Community  
Medicine



The-Partnership-for-Native-American-Cancer-Prevention



@NacpOutreach