

How to Review Research to Benefit Tribal Communities



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This document is a guide for tribal communities on:

- Research in American Indian and Alaska Native Communities;
- Questions to Ask during the Research Review Process;
- Community-based Participatory Research; and
- Additional Resources.

Research in American Indian and Alaska Native Communities

Over the past several decades, there has been an increase in the amount of research occurring in Indian Country. Research takes many forms and is the study of something in order to learn new things.

A large part of the increase in research is due to the advent of Tribal-based Epidemiology Centers and the Native American Research Centers for Health (NARCH) initiatives. These initiatives are in response to tribal self-determination and the need to understand the causes and determinants of disease impacting American Indians and Alaska Natives (AI/AN). Other research are investigator initiated projects, oftentimes, by University-based researchers.

In order for research to be beneficial to AI/AN, it is important to empower and enable tribes to review research with an eye to maximizing benefit and protecting individual participants and the tribal community. In this guide, we offer a brief overview of what to assess during a review. We also provide other resources that go into more 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 Conduct Research in American Indian and Alaska Native Communities, Volume III
- 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*.

Ultimately, the research being conducted should minimize risks and maximize benefits for AI/AN communities from a cultural/traditional, physical, psychological, spiritual, social, economic and legal perspective.

We also recommit to supporting tribal self-determination, security, and prosperity for all Native Americans. --Barrack Obama

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Questions to Ask during the Research Review Process

It is important to remember that the purpose of tribal governments is to govern their respective societies, which is an inherent right to self-government. Tribes are sovereign nations. Tribes have the right to approve or disapprove proposed research. Tribes have the right and responsibility to optimize the benefits of the research for the participants and for the tribal community at large.

Significance

- How is the research addressing tribal needs?
- How is the tribe benefitting from the research?
- What are the potential harms? Are they being addressed adequately?

Approach

- How is the information being collected?
- What information is being collected?
- Who is going to be collecting the information?

Data / Information

- Will personal information be collected?
- How is the information being protected? Who has access to the information?
- How long is the information going to be stored? Where?
- Will the tribe own the data?

Participants

- Who is being included?
- How many individuals are being included?
- Are there children, or others that may need additional considerations being included?

Consent

- Is the consent written in a way that will be easily understood?
- Are translators needed? Is an interpreter needed?
- Are all elements of the project included in the consent form?
- Are individuals being given enough time to make a determination of whether or not to participate?

Questions

- What questions are being asked?
- Are the questions okay to be asked?
- How long will it take to ask the questions?
- If questions are sensitive, is privacy being secured?

Biospecimens

- What is being collected?
- How is the information being protected? Who has access to the information?
- How long is the information going to be stored? Where?
- Will the data be able to be destroyed?

Privacy / Confidentiality

- How are personal identifiers being handled, for example, name, phone numbers, etc.
- Are participants being told how their information will be protected?
- How is the tribal community being protected?

Referrals

- Are individuals receiving referrals in case there is need for follow-up?
- Are individuals receiving contact lists of someone to call in case they need to talk with someone?
- How are individuals needing follow-up being identified?

Liability

- Who is responsible if something goes wrong?
- Are there conditions under which data might be released? e.g., court order
- What happens if anyone is physically, emotionally, or spiritually hurt?

Capacity Building

- How are tribal community programs being included?
- Are tribal community members being included to help with the research?
- What resources are being allocated to the tribe?

Reporting

- How frequently should the researchers provide updates?
- How will the community be informed of findings?
- Will the tribe review before public dissemination?

Publication

- What are the tribal requests for how abstracts, manuscripts and reports will identify the tribe?
- Will tribal partners and/or the tribe be co-authors?

Next Steps

- What happens to the information that was collected?
- How long will it be stored? Who has access?
- How will data be destroyed? by whom?

Community-based Participatory Research (CBPR) is “a partnership approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process and in which all partners contribute expertise and share decision-making and ownership.”¹ CBPR is an increasingly acceptable approach to tribal communities for establishing research partnerships. Although CBPR exists on a continuum, most partnerships are built on these fundamental principles: 1) recognize community as a unit of identity; 2) build on strengths and resources of the community; 3) facilitate collaborative partnerships in all phases of the research; 4) integrate knowledge and action for the mutual benefit of all partners; 5) promote a co-learning and empowering process that attends to social inequalities; 6) involve a cyclical and iterative process; 7) address health from both positive and ecological perspectives; and 8) disseminate findings and knowledge gained to all partners.² *Tribal Participatory Research (TPR)* approaches are viewed as particularly ethical and respectful of research partnerships with sovereign tribal nations.^{3,4} CBPR/TPR partnerships allow research to be responsive to community needs, to be culturally appropriate, and to be strengths-based while being mindful of the unbalanced and often harmful research previously conducted in tribal communities.

Resources

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

The **University of Arizona Human Subjects Protection Program** provides information on human subjects protection. <https://rgw.arizona.edu/compliance/human-subjects-protection-program/about-the-irb>

Northern Arizona University Human Research Protection Program provides information on human subjects protection. <https://nau.edu/nau-research/research-safety-and-compliance/human-research-protection-program/>

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 **National Congress of American Indians** has information about the foundations, ethics, and practices of research resulting in the construction of AI/AN codes, contracts, and IRBs at: <https://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/>

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

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

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

References

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² Israel BA, et al. Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998; 19:173–202.

³ Fisher PA, Ball TJ. Tribal participatory research: Mechanisms of a collaborative model. *American Journal of Community Psychology*. 2003; 32(3-4):207–216. [PubMed: 14703257]

⁴ Thomas LR, Donovan DM, Sigo RLW. Identifying community needs and resources in a Native community: A research partnership in the Pacific Northwest. *International Journal of Mental Health and Addiction*. 2010; 8(2):362–373.

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