



RESEARCH AT THE SPEED OF TRUST

A guide for researchers and Native communities



National American Indian & Alaska Native

PTTC

Prevention Technology Transfer Center Network
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Research at the Speed of Trust: A guide for researchers and Native communities

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At the time of this publication, Miriam Delphin-Rittmon served as Assistant Secretary for Mental Health and Substance Use and Administrator of SAMHSA.

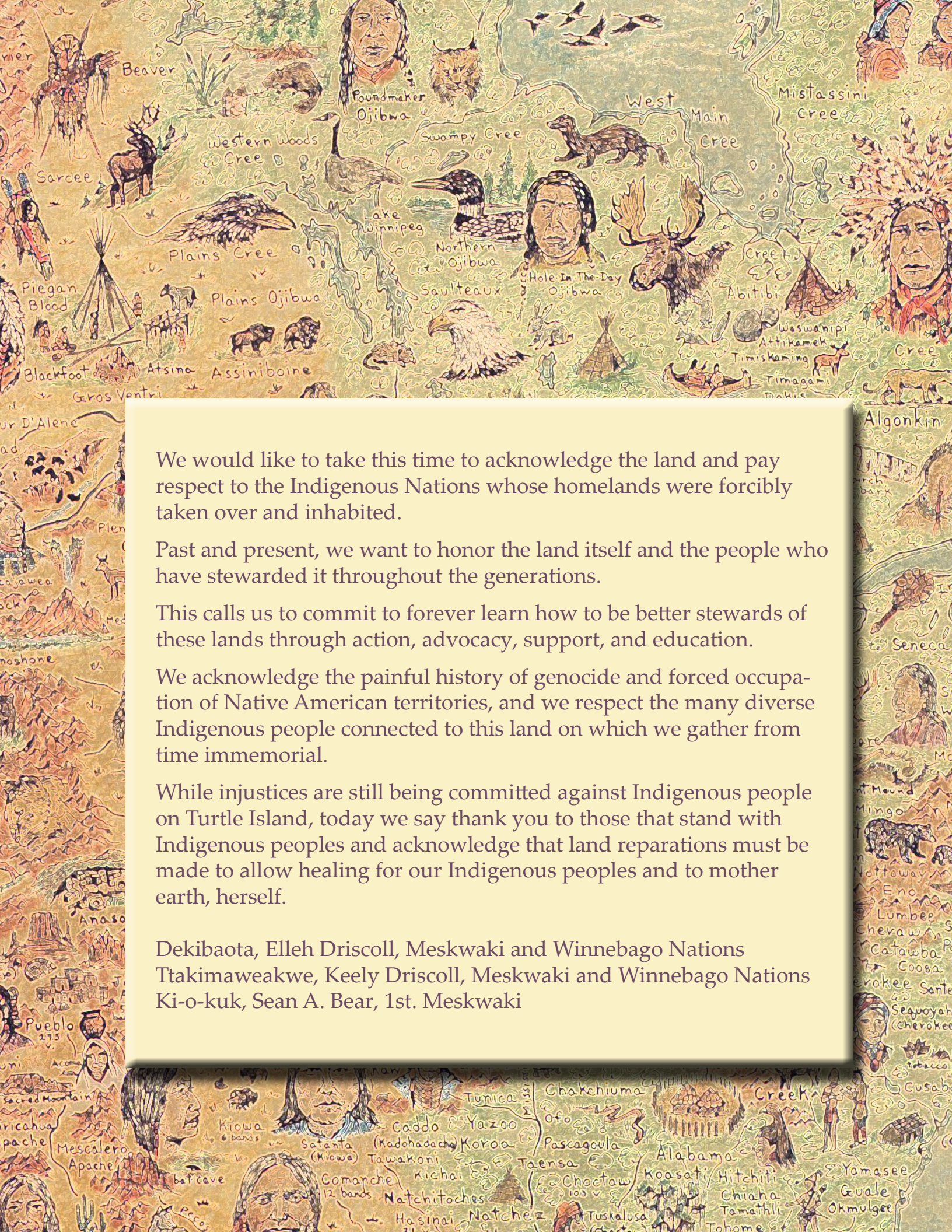
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A word about the title: The origin of the phrase "speed of trust" is murky, but our colleague **Rima Afifi, PhD**, professor and director of the Prevention Research Center for Rural Health at the University of Iowa College of Public Health, frequently tells her students, "Research happens at the speed of trust." We thank her for inspiring the title of this guide.

Finally, we wish to acknowledge the Substance Abuse and Mental Health Services Administration, which has provided funding and technical support for the National AI/AN Technology Transfer Centers for several years.



We would like to take this time to acknowledge the land and pay respect to the Indigenous Nations whose homelands were forcibly taken over and inhabited.

Past and present, we want to honor the land itself and the people who have stewarded it throughout the generations.

This calls us to commit to forever learn how to be better stewards of these lands through action, advocacy, support, and education.

We acknowledge the painful history of genocide and forced occupation of Native American territories, and we respect the many diverse Indigenous people connected to this land on which we gather from time immemorial.

While injustices are still being committed against Indigenous people on Turtle Island, today we say thank you to those that stand with Indigenous peoples and acknowledge that land reparations must be made to allow healing for our Indigenous peoples and to mother earth, herself.

Dekibaota, Elleh Driscoll, Meskwaki and Winnebago Nations
Ttakimaweakwe, Keely Driscoll, Meskwaki and Winnebago Nations
Ki-o-kuk, Sean A. Bear, 1st. Meskwaki



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Preface

Western-based research unfortunately has some major scandals in its history (the infamous [Tuskegee Syphilis Study](#), and, more recently, the [ASU-Havasupai DNA](#) scandal), which have deepened Indigenous distrust of outsiders. Western-based research methods also often disregard Indigenous traditions, values, and ways of knowing. For example, the principles of the 1978 Belmont Report on ethical human subject research focus on individuals rather than communities. Likewise, a typical academic Institutional Review Board does not consider interviews with community members to qualify as “human subject research” and therefore may not require informed consent. But many Native communities expect to know exactly what such interviews are intended to reveal, how the information will be used, how it will benefit their community, and how their community will be protected from harm – all elements of informed consent.

In short, conducting research in Indigenous communities is **not** the same as conducting research anywhere else. This document is intended as a broad guide for researchers and Indigenous communities to help them understand some of the complexities they may encounter and elements they must consider when approaching research with Native populations. It is our hope that this guide will help researchers and the Indigenous communities they work with to avoid common pitfalls, improve their relationships, and strengthen the value of their research efforts.



Introduction

Western-based research has long aspired to be culturally neutral, and many have argued that the widely accepted principles of ethical research (respect for persons, beneficence, and justice, from the Belmont Report, 1978) achieve this goal. But some have begun to question whether cultural neutrality in research is possible, or even desirable (Westra, A.E., Willems, D.L. & Smit, B.J. Communicating with Muslim parents: “the four principles” are not as culturally neutral as suggested. (Eur J Pediatr 168, 1383–1387, 2009, <https://doi.org/10.1007/s00431-009-0970-8>).

When it comes to ethical research involving Indigenous communities, the Western principles of respect for persons, beneficence, and justice are merely a starting point. Historically, the relationship between researchers and Indigenous communities has been more exploitative than mutually beneficial, and this history has made many Indigenous communities understandably wary of researchers – whether the researchers be outsiders or members of their own community – and the potential for harmful effects of any research.

In this guide, we intend to provide a resource for researchers and Indigenous communities to help both understand the specific viewpoints and ethical considerations that must be taken into account. Every Indigenous community is different, with its own cultural norms, ways of knowing, and processes for approaching and handling research within its community. One of the guiding principles for the Native Center for Behavioral Health and the National American Indian and Alaska Native Prevention Technology Transfer Center is that Indigenous communities are the experts on their own needs and what works for them. Therefore, this publication is by no means an exhaustive reference for either researchers or Indigenous communities, but rather is intended to serve as a resource to further understanding of general principles that facilitate a better working relationship between researchers and Indigenous communities.

With that goal in mind, we have divided this guide into two sections: one covering critical aspects for researchers to consider as they approach their work with Indigenous communities, and the second supplying resources for Indigenous communities to protect themselves from potential harm while availing themselves of the benefits of well-conducted research.

Important Definitions

American Indian/Alaska Native: A member of any of the Indigenous peoples of the Americas. We recognize that there are a number of other preferred terms. We also recognize that there are Native peoples outside of the United States, but for the purposes of this document, we refer to Indigenous peoples of, or residing in, the United States when we use the term American Indian. Due to differences in law, including but not limited to the Alaska Native Claims Settlement Act (ANCSA), the term 'Alaska Native' signifies the ethnic, cultural, and historical differences between the Indigenous peoples of Alaska and those of the Lower 48 states and Hawai'i, and this is the preferred referent in Alaska (Straits et al., 2012). In this document, we use Indigenous and Native interchangeably to refer to American Indian and Alaska Natives in the U.S.

Community: There is no single definition of community that applies to every situation. This term can be co-defined with partners in the research process. For example, a Native community could refer to an entire tribe, an entire village, smaller groups within the tribe, an urban Native community composed of individuals from different tribes, or the larger American Indian/Alaska Native community within a city, state, country, or the globe (Straits et al., 2012).

Community-Based Participatory Research: A collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.

Cultural Humility: A commitment and active engagement of continual self-evaluation regarding the interaction and impact of one's culture(s) on a given situation or relationship so as to cultivate mutually beneficial partnerships that recognize and remedy any power imbalances (Straits et al., 2012).

Culture: Culture and traditions vary greatly among Native American communities. Native American individuals and communities also vary in adherence to their cultures of origin and to Western cultural values and beliefs. For many Native American people, spirituality and religion are generally perceived as an integral aspect of culture. Spirituality also takes on many forms within Native American communities, from use of traditional Indigenous practices to Christian beliefs (Straits et al., 2012).

Non-Native: An individual who is not a member of the Indigenous peoples of the Americas. We recognize the diverse histories of researchers of different races. We have selected this general term to increase the applicability of this document to researchers of all races/ethnicities not of Native American descent or heritage. This encourages the reader to consider differences in historical experiences, assumptions, and stereotypes (Straits et al., 2012).

Sovereignty: Sovereignty is the authority of a state or nation to govern itself. Tribal sovereignty in the United States includes the principle that federally recognized Indigenous tribes have retained the inherent authority for self-governance. However, the federal government recognizes tribes as "domestic, dependent nations," meaning that they have limited sovereignty in matters beyond their recognized territory or membership because of treaties, federal statutes, tribal laws, and federal court decisions (Straits et al., 2012).

Tribal: For space considerations, we use the term "tribal" to refer to communities, governments, and other entities associated with Indigenous peoples. Terms like "tribal councils" in this document thus refer to such entities both in the contiguous U.S. and to Alaska Native Village entities.

Source: Straits, K. J. E., Bird, D. M., Tsinajinnie, E., Espinoza, J., Goodkind, J., Spencer, O., ... & Willging, C. (2012). Guiding principles for engaging in research with Native American communities. Albuquerque, NM: UNM Center for Rural and Community Behavioral Health & Albuquerque Area Southwest Tribal Epidemiology Center.





SECTION I: Guiding Principles for Researchers

As of this writing, there are 574 federally recognized American Indian and Alaska Native (AI/AN) tribes and villages in the United States, each of them a sovereign nation (Bureau of Indian Affairs, 2022; Gachupin & Molina, 2019). There are hundreds more tribes that are recognized by state governments, and countless others that, for a variety of reasons, are not officially recognized by either a state or the federal government.

Regardless of its recognition status, every tribal government has its own requirements to conduct research on its land. It is crucial for researchers to build a relationship with the tribal entities involved in the study and to learn the tribal requirements to conduct research (UAF, n.d.).

Relationship development within Native communities stems from a continual and intentional effort to gain understanding of both cultural and research protocols within the Native community. **Researchers should not expect tribal research processes and protocols to mimic those found at, for example, U.S. academic institutions.** For one thing, the investment of time and effort to establish and build a trusting working relationship with Indigenous communities is unlikely to mesh well with traditional Western-based timelines.

Just as important, researchers must invest in understanding and acknowledging historical injustices and trauma of the community they wish to work with. These tribal experiences will differ from community to community and therefore it is the researcher's responsibility to listen well and respond appropriately to a particular community's concerns. The 2012 publication *Guiding Principles for Engaging in Research with Native American Communities* (UNM Center for Rural and Community Behavioral Health & Albuquerque Area Southwest Tribal Epidemiology Center (https://hsc.unm.edu/vision2020/common/docs/Guiding_Principles_Research_Native_Communities2012.pdf)) includes these insights:

-  **Establish Relationships.** Get to know the tribal communities and establish relationships early on with Elders and spiritual leaders who can serve as mentors, guides, and facilitators throughout the evaluation.
-  **Native Centered.** Native communities and people should be the driving force of the research, involved in every step of the process from beginning to end. Research activity and action are centered on issues that are central to the Native community, not the research center, sponsoring institution, or agency.
-  **Appreciate History and Culture.** Develop an appreciation of the tribe's history and culture. This should include an awareness and a clear understanding of any historical trauma experienced by the tribe.
-  **Respect.** Respect and honor tribal sovereignty, cultural traditions, and diversity among and within Native communities. This can be done by seeking understanding of the community and their needs of research as well as being aware and respectful of existing community protocols.



Conducting research with Indigenous communities is a continual cycle of building and strengthening relationships through every phase of research. This graphic represents the cycle and what is needed at each stage (reprinted from [Guiding Principles for Engaging in Research with Native American Communities](#)).



Why Procedures Matter in Native Communities

The case of Havasupai Tribe vs. the Arizona Board of Regents

Background: In 1989, approximately 100 Tribal members of the Havasupai Tribal Community signed a broad consent document to “study the causes of behavioral/medical disorders” which was presented from Arizona State University (ASU). All members of the Tribe were led to believe that they were donating blood samples for the sole purpose of further understanding why more than half of Havasupai adults suffer from diabetes. This better understanding was expected to help identify ways to improve health in their community. ASU researchers determined that the genetic link to diabetes found in other tribes were not present among the people of the Havasupai Tribe; however, the research team continued research into medical disorders without seeking additional consent. Additional research included publications on topics such as inbreeding, alcoholism, and theories about the origin of the Tribe, which were not initial areas of research presented within informed consent.

Outcome: The additional studies serve to violate informed consent, and theories about the tribe’s origin conflicted with their core beliefs. The Havasupai tribe’s experience demonstrates the extensive harm that can be done to a community – some of it irreparable – through violation of informed consent. The research subjects were not adequately informed about how their DNA would be used at the university, and this significantly impacted the integrity of their community and their trust of outsiders.

Implication for Future Research: It is vital that a researcher respect the community and its values and beliefs and follow the principles of human subject research, namely, obtaining informed consent from the community. Not only can failure to adhere to informed consent protocols be devastating to a community, but it can also permanently damage the credibility of a researcher or institution.

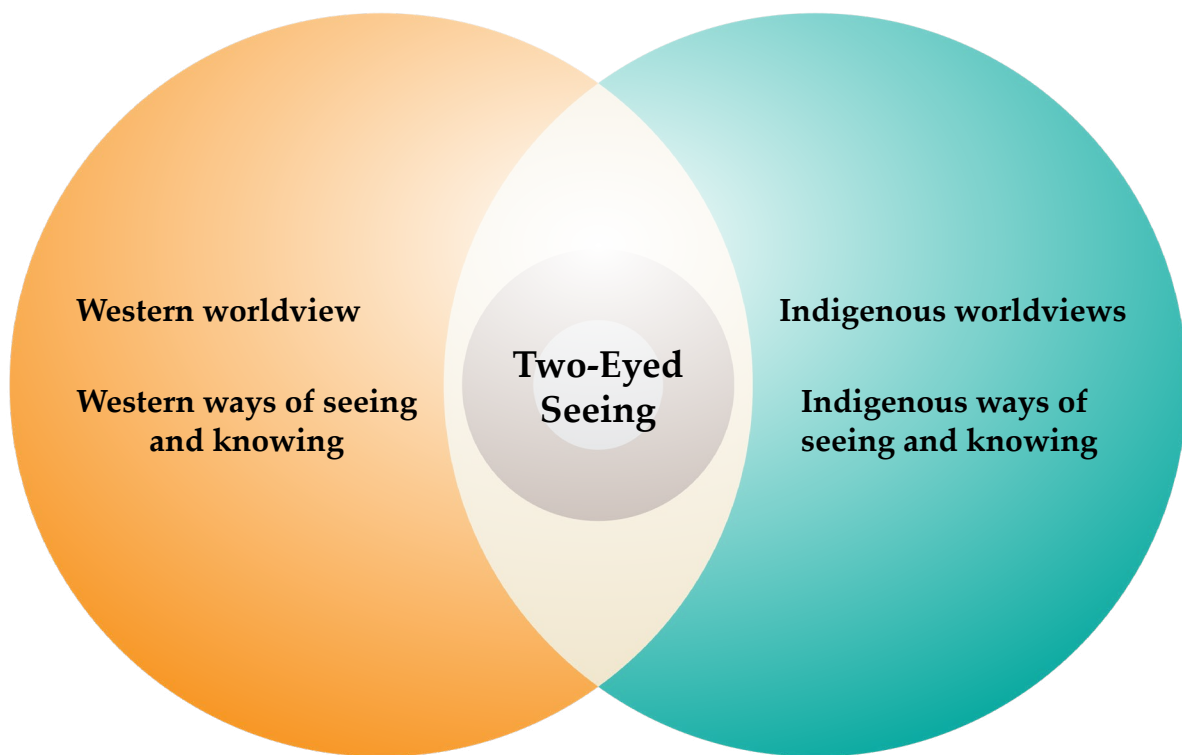
Sterling , R. L. (2011). Genetic research among the Havasupai: A Cautionary Tale. AMA Journal of Ethics, 13(2), 113–117. <https://doi.org/10.1001/virtualmentor.2011.13.2.hlwa1-1102>

*Havasupai Falls, Havasupai Reservation,
Arizona (Shutterstock)*



Two-Eyed Seeing

The Native Center for Behavioral Health at the University of Iowa and the National American Indian and Alaska Native Prevention Technology Transfer Center (PTTC) endorse a practice known as Two-Eyed Seeing (Marshall & Bartlett, 2010).



Adapted from Marshall, A., & Bartlett, C. (2010, March)

Indigenous people, who have had to adapt over centuries to the imposition of Western thought, laws, processes, and procedures, are well acquainted with the concept of Two-Eyed Seeing, essentially combining the respective strengths of Indigenous and Western worldviews and ways of knowing.

“Two-Eyed Seeing refers to learning to see from one eye with the strengths of Indigenous ways of knowing and from the other eye with the strengths of Western ways of knowing and to using both of these eyes together.”

Bartlett, Marshall & Marshall, 2012

Two-Eyed Seeing requires researchers to recognize and respect the thousands of years of experimentation, adaptation, and experience Indigenous peoples have invested to learn, for example, which plants have medicinal properties for which ailments, which foods promote their best physical, mental, spiritual, and emotional wellbeing, and so on. Prior to European contact, Indigenous ways of knowing were rarely (if ever) documented the way Western practices were, but that does not make them less valid.

NOTE: Two-Eyed Seeing does not require researchers to hold all the knowledge of a particular Indigenous community. Indeed, that would be both impossible and, in many cases, inappropriate; in many Indigenous communities, some knowledge (sometimes called “sacred knowledge”) is not intended for all, even within the community (NCAI Policy Research Center and MSU Center for Native Health Partnerships, 2012).

Successful application of Two-Eyed Seeing also requires the researcher to commit to relationship-building, community control of the process and resulting data, and collaborative analysis, and to find ways the research will benefit the community (Jeffery, 2021).

Combining data and storytelling

Western-based research often focuses on quantitative data, while Indigenous ways of knowing often focus on stories that teach a lesson. There is value for both researchers and Indigenous communities in combining the two — in other words, using data to tell a story or using a story to illustrate the need for more or better data. For example, one Southwestern Indigenous community used a story of impaired vision to illustrate the “blind spots” in their substance use disorder treatment program. The story helped community leaders understand why it was important to collect data to find out where the gaps were, and the data then helped the community craft a more holistic (and therefore more effective) treatment program by minimizing the program’s blind spots.

Community-Based Participatory Research

The process of acknowledging historical injustices and inclusion of tribal practices and community members within the research process provides the foundation for Community-Based Participatory Research (CBPR) (HHS, 2018).

The core principle of the CBPR model is that, from beginning to end, research must involve a full partnership between the researchers and the communities being studied (Mariella et al, 2009). Widely accepted foundational principles of CPBR include:

- ✓ Recognition of community, rather than merely individual, values, and goals
- ✓ Development of full partnerships between researchers and study communities
- ✓ Community involvement in all aspects of the research process
- ✓ Community empowerment to build its own research capacities

Over the past 20 years, a growing body of literature has expounded on a CBPR variation called Tribally Driven Participatory Research (TDPR), which emphasizes full participation of tribal governments from the earliest stages of research and empowering Indigenous communities to build their internal capacity for conducting important research. In fact, some aspects of TDPR have been around since the Great Depression. As Mariella notes:

“On the positive side, there are historical examples of individual researchers and government-funded projects that have succeeded in achieving at least some of the desired results of TBPR, particularly in improving health (Arizona Biomedical Research Commission, 2006). Often cited are the research project on sulfa antibiotic treatment for trachoma (eye infections) in the 1930s with the White Mountain Apache, as well as the clinical trials, championed by Annie Wauneka at Navajo in the 1950s, on isoniazid (INH), which proved effective in treating tuberculosis (Davis & Reid, 1999).”

The major difference between CBPR and TDPR is that, unlike most other communities in the U.S., Indigenous communities do not have to act merely as a base for research. Tribal governments have the legal authority to actively control and drive research within their boundaries. This authority means that researchers must recognize that the systems they are accustomed to likely are not sufficient to successfully conduct research with Indigenous communities. (Refer to our pocket guide, *Understanding Tribal Sovereignty: Seeking approval for prevention and research efforts*, for more information on this topic, or order print copies by emailing cph-nativecenter@uiowa.edu.)

When working with tribes, approval from your own IRB is not enough. You may have to work with tribal leadership first, then with a tribal IRB, community advisory board, or ethics committee, and perhaps with the entire community, to receive approval for your project.

Just as institutions require a review and approval process (usually an Institutional Review Board, or IRB) for research purposes, neither research nor data collection within tribal communities should begin without tribal approval or clearance. This could be in the form of a Tribal IRB, a Community Advisory Board, an ethics committee, a Tribal council, or some combination of these. Some Indigenous communities work with the Indian Health Service (IHS), a tribal college or university, or another university or research institution to regulate research. Like any other IRB, tribal IRBs assume responsibility for the ethical review and oversight of all research occurring on their tribal land, including protection of human subjects, the tribe, tribal communities, and tribal resources.

The Common Rule, updated in 2019 to specifically include tribal governments, affirms that each tribe may have its own definition of research and its own set of research protections and laws that may be more rigorous and restrictive than the Common Rule.

In addition to the researcher's own organization's IRB process and approval, a researcher must also receive appropriate approvals and review from the tribe throughout the process.

Benefits to IRB Inclusion:

- Ensures more areas of protection for the community
- Creates opportunity for inclusion of tribe-specific values to research regulation
- Requires collaborative efforts between researchers and tribal members through written agreement
- Provides prevention against research-related harm to individuals and community
- Ensures that tribes benefit from research conducted on tribal land

IRB Types

The map below shows where Indian Health Service (IHS) national and area IRBs are located. The chart on the next page provides additional information about these IRBs, as well as Independent Tribal IRBs listed on the IHS website.

- **IHS Area IRB:** Reviews all projects in their specific areas and makes decisions on each
- **IHS National IHS IRB:** Reviews the protocols sent to them by the Area IRB Chairs for review; reviews all AI/AN protocols from the Areas that have no local IRB
- **Tribal and Independent Tribal Organization IRBs:**
 - Tribes may provide their own IRBs (i.e., Cherokee Nation, Chickasaw Nation).
 - Tribes may rely on Tribal College/University IRBs.
 - Tribes may rely on other independent tribal organizations.
 - Tribes may have a review committee, which is not an IRB but serves a similar function.
 - Tribes may work with their Tribal Councils or health and/or legal departments for reviews.



IHS Institutional Review Boards (IRB)



Contact information for these IRBs can be found at <https://www.ihs.gov/dper/research/hsrp/instreviewboards/>

Indian Health Service IRBs	National IRB (NIRB) at IHS Headquarters, Rockville MD
	Alaska Area
	Bemidji Area
	Billings Area IHS/Rocky Mountain Tribal
	Great Plains Area
	Nashville Area
	Navajo Area
	Oklahoma City Area
	Phoenix Area
	Portland Area
Tucson Area	
Independent Tribal IRBs	American Indian Healing Center, Inc.
	Association of American Indian Physicians
	Blackfeet Nation
	California Rural Indian Health Board (CRIHB)
	Cherokee Nation
	Chickasaw Nation
	Choctaw Nation
	College of Menominee Nation
	Fond du Lac Band of Lake Superior Chippewa
	Haskell Indian Nations University
	Ho-Chunk Nation IRB
	Southwest Tribal IRB (Albuquerque Area)
	Oglala Sioux Tribal Research Review Board (OSTRRB) (Great Plains)
	Sisseton-Wahpeton Oyate Local Research Review Board (SWOLRRB) (Great Plains)
Tribal Nations Research Group (TNRG) (Great Plains)	

REMEMBER: Each tribe has its own procedures for approving external research or program implementation. It is best to seek guidance from the tribe on what is expected and the appropriate steps to take. Approval processes can take time and must be built into the timeline of the project. This extra investment of time and effort is crucial because the ethical implications of conducting research with Indigenous communities may be both broader and more complex than any other research relationship.

Respectfully Engaging Indigenous Communities

There is a story about a group of researchers who desperately wanted to interview an Indigenous community's Elders for an academic paper. The community repeatedly demurred, but the researchers refused to take no for an answer and continued to press for access to the Elders. Finally, weary of the pressure, the community got the Elders together and had them talk to the researchers. The researchers went away and published their paper, unaware that nothing the Elders had told them was a true representation of their experiences or culture.

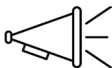
Respect is at the heart of virtually all relationships with Indigenous peoples. Refuse to respect their autonomy, their lived experiences, their traditions, or their protocols, and your research findings may not be accurate.

Here are some ways researchers can demonstrate respect for the Indigenous communities they hope to work with:



Recognize

- Community right to decline participation
- Harms and benefits at the community and individual levels
- Community trust/distrust in research
- Community experiences with discrimination, stigmatization, and stereotyping



Promote

- Transparency throughout the full research process
- Community values and protocols to be included in the research process
- Proper ownership of data
- Protection of participant and tribal policy

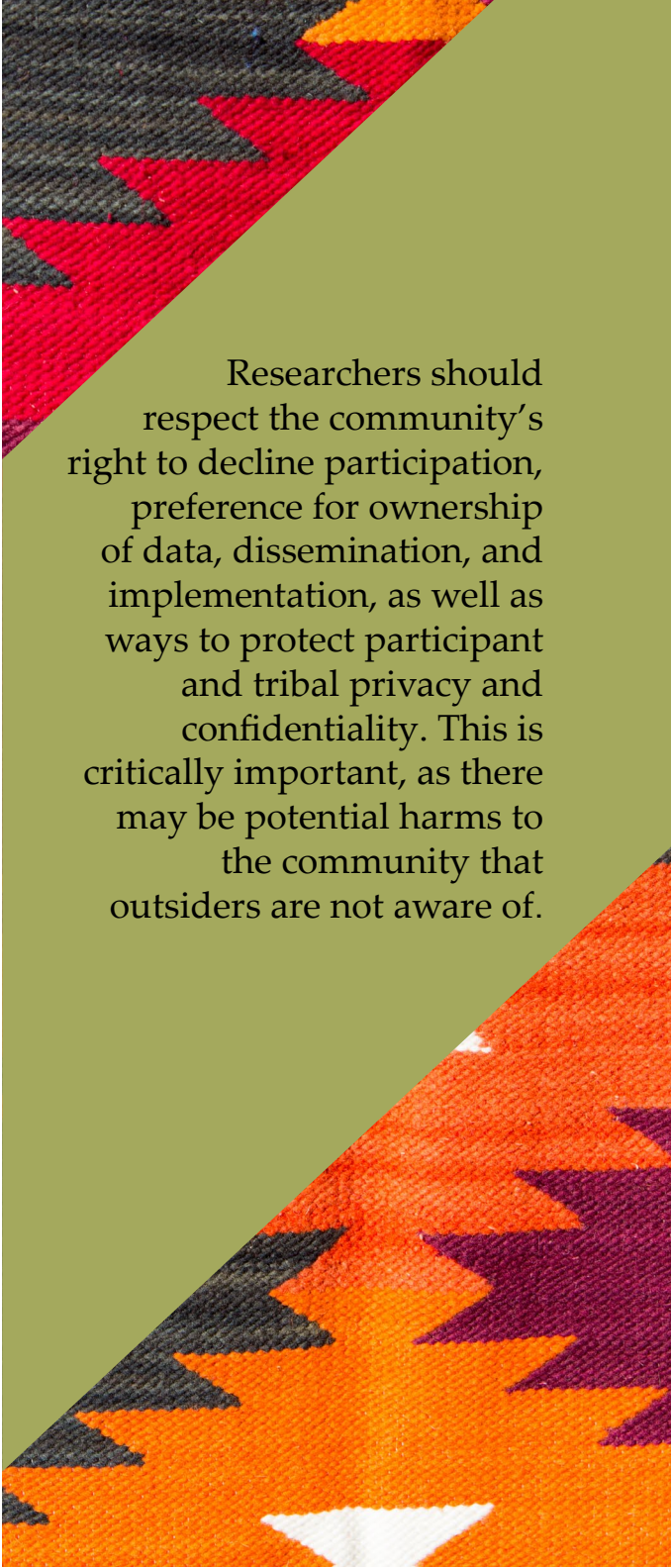


Collaborate on

- How to handle dissemination and any action arising from research findings
- How to handle any additional research findings
- Processes for managing and accessing data and results
- Assistance in addressing research findings within the community

The following list of practical tips for including culture in research is drawn from the NCAI Policy Research Center curriculum, [Research that Benefits Native People: A Guide for Tribal Leaders](#):

- ❖ Be open to using a variety of types of research questions.
- ❖ Realize that the answers or outcomes of research may mean different things to different people.
- ❖ Involve community members in a meaningful way; research is strongest when community and researchers join together in every step of the research process.
- ❖ Use accessible language that is easy to understand and Native focused (when appropriate).
- ❖ Accept that outside researchers must learn and attempt to understand the tribal culture to be most effective.
- ❖ Use a broad, representative group of stakeholders to ensure that cultural considerations are well represented in the research.



Researchers should respect the community's right to decline participation, preference for ownership of data, dissemination, and implementation, as well as ways to protect participant and tribal privacy and confidentiality. This is critically important, as there may be potential harms to the community that outsiders are not aware of.

Researchers must ensure that their efforts to engage Indigenous communities are both genuine and representative – and recognize that “representative” may have a different meaning within an Indigenous community. If your research focuses on youth and young adults, for example, do not assume that the community's Elders should not be consulted or included. Ask the community what “representative” looks like to them.

Culturally Informed CBPR

The graphic below outlines some steps for conducting culturally informed CBPR in Indigenous communities. Note that the six broad areas touch one or more other areas; this is because working with Indigenous peoples is not typically a linear process, but rather a continual cycle that strengthens with every revolution.



Informed Consent: Areas to Include

<input type="checkbox"/> A statement that the study involves research, an explanation of the purposes of the research, expected duration of the participant's participation, a description of the procedures to be followed, and identification of any procedures which are experimental.
<input type="checkbox"/> A description of any risks or discomforts to the participant.
<input type="checkbox"/> A description of any benefits to the participant or to others which may reasonably be expected from the research.
<input type="checkbox"/> A disclosure of appropriate alternative procedures or courses of treatment, if any, that might be advantageous to the participant.
<input type="checkbox"/> A statement describing the extent, if any, to which confidentiality of records identifying the participant will be maintained.
<input type="checkbox"/> For research involving more than minimal risk (minimal risk means that the probability of harm or discomfort anticipated in the research is not greater than those ordinarily encountered in daily life), an explanation as to whether any medical treatments are available if injury occurs and, if so, what they consist of, or where further information may be obtained.
<input type="checkbox"/> An explanation of whom to contact for answers to questions about the research and research participant's rights, and whom to contact in the event of a research-related injury to the participant.
<input type="checkbox"/> A statement that participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which the participant is otherwise entitled, and the participant may discontinue participation at any time without penalty or loss of benefits to which the participant is otherwise entitled.
<input type="checkbox"/> The approximate number of participants involved in the study.
<input type="checkbox"/> The procedures for orderly termination of participation by the subject, and the consequences of a participant's decision to withdraw from the research.
<input type="checkbox"/> Any additional costs to the participant that may result from participation in the research.
<input type="checkbox"/> Anticipated circumstances under which the participant's participation may be terminated by the investigator without regard to the subject's consent.
<input type="checkbox"/> When appropriate, a statement that the particular treatment or procedure may involve risks to the participant (or embryo or fetus, if the subject is or may become pregnant) which are currently unforeseeable.
<input type="checkbox"/> When research protocol involves biological samples, a statement that the participant must designate to have their biological samples destroyed or returned to the participant or the participant's heir, or if none then to the community; and the option to have samples destroyed or returned upon death of the participant.*
<input type="checkbox"/> Identify the research project contact for the community.

* NOTE: The retention and ownership of biological samples (e.g., blood, saliva, tissues, etc.) is a sensitive issue in Native communities (see the Havasupai experience summarized on page 11). Tribal authorities may wish to address this in an MOU or other formal document; in that case, the agreed-upon procedure should be listed in the consent form. Another approach, depending on the community's preferences and concerns, is to offer a list of options on the consent form, so participants can choose whether they want their samples returned, destroyed, or preserved for future research.

Additional Resources

<p>The Collaborative Research Center for American Indian Health (CRCAIH)</p>	<p>CRCAIH Tribal IRB Toolkit https://www.crcaih.org/irb-toolkit.html</p> <p>CRCAIH Research Data Management Toolkit Version 2. 0 https://www.crcaih.org/training-and-resources/data-management-toolkit.html</p>
<p>Native American Center for Excellence Substance Use Prevention</p>	<p>Steps for Conducting Research and Evaluation in Native Communities https://www.samhsa.gov/sites/default/files/nace-steps-conducting-research-evaluation-native-communities.pdf</p>
<p>The Partnership for Native American Cancer Prevention</p>	<p>How to Conduct Research in American Indian and Alaska Native Communities https://naair.arizona.edu/sites/default/files/how_to_conduct_research_201936.pdf</p>
<p>Seattle Indian Health Board – Urban Indian Health Institute</p>	<p>Best Practices for American Indian and Alaska Native Data Collection https://www.uihi.org/resources/best-practices-for-american-indian-and-alaska-native-data-collection/</p>
<p>UNM Department of Psychiatry Center for Rural and Community Behavioral Health</p>	<p>Guiding Principles for Engaging in Research with Native American Communities https://hsc.unm.edu/vision2020/common/docs/guiding_principles_research_native_communities2012.pdf</p>
<p>Indigenous Evaluation Toolkit: An Actionable Guide for Organizations Serving American Indian/Alaska Native Communities through Opioid Prevention Programming</p>	<p>Seven Directions: A Center for Indigenous Public Health, University of Washington https://assets.website-files.com/5d4b-3177c03a6439be501a14/63f550f6aca5a76fe-89c290a_FINAL_7D_EvalToolKit_FullDoc_022123_WEB_compressed.pdf</p>

SECTION II: Resources for Indigenous Communities

The Native Center for Behavioral Health and the National American Indian and Alaska Native PTTC operate under the principle that Indigenous communities are the experts on what they need and what works for them. We do not presume to dictate to these communities how they should view research as a whole or how they should approach conducting research either with community members or with outside researchers. Instead, in this section, we offer resources and guidance on things to consider in relation to research within their communities.

“Evidence-based practices” show up regularly in research literature, but too often the published evidence does not include Natives or other people of color. Although Indigenous people have been studied (albeit unethically) extensively over the past 400 years, they continue to be under-represented in most major studies. Regardless of the topic, the lack of inclusion of Native people results in imperfect conclusions about what works and what doesn’t in Indigenous communities.

Indigenous communities are increasingly advocating for better data to help them develop policies and programs that are effective and beneficial for their unique needs.

The most effective way to remedy the gap in the published data is for Indigenous communities to take an active role in soliciting, developing, conducting, and regulating research. Collecting high-quality data and reliable research gives tribal leaders and communities the tools to:

- ◇ Make informed decisions about issues the community is facing
- ◇ Take positive action to address issues and shape the community’s future
- ◇ Pursue funding opportunities to implement programs that benefit the community
- ◇ Make necessary refinements to existing programs, and
- ◇ Invest in research relevant to their community

Resources for Indigenous Communities

For Indigenous communities looking to begin or strengthen their own research programs, consider the following resources (part of a list compiled by the NCAI Policy Research Center):

Alaska Native Knowledge Network Resources

The [Alaska Native Knowledge Network](#) (ankn.uaf.edu) at the University of Alaska Fairbanks provides a number of resources related to Alaska Native knowledge and ways of knowing:

- ◇ [Principles for the Conduct of Research in the Arctic](#)
- ◇ [Principles & Guidelines for the Protection of the Heritage of Indigenous People](#)
- ◇ [Alaska Federation of Natives Guidelines for Research](#)

American Indian Law Center Model Tribal Research Code (<https://www.sprc.org/sites/default/files/resource-program/ModelTribalResearchCode1999.pdf>) explores the general role of research and Institutional Review Boards in the federal regulatory process for American Indian tribes. It presents a model code to assist tribes in developing law regarding their research regulations and needs.

University of Arizona, Native Peoples Technical Assistance Office, Research Protocols (<https://naair.arizona.edu/about/nptao>) provides a [database](#) of U.S. tribes' research ordinances, codes, and protocols. Additional resources include template research codes, model research agreements, and a bibliography on academic research in Indian Country.

Indigenous Peoples Council on Biocolonialism

This international organization (ipcb.org) offers fill-in-the-blank templates for [academic research agreements](#) and a sample [Indigenous Research Protection Act](#) for tribes wishing to formalize their policies and protocols for research in their communities.

Indigenous Wellness Research Institute, University of Washington (iwri.org/resources/research-resources) offers [templates on several research-related topics](#), developed in partnership by the University of Washington and Pacific Northwest tribes:

- ◇ Data use agreement
- ◇ Code of ethics and integrity
- ◇ Publication and dissemination guidelines
- ◇ Student involvement in the research team
- ◇ Sample tribal resolution
- ◇ Sample research protocol code

National Congress of American Indians Policy Research Center (ncai.org/prc) offers a series of papers on research regulation in American Indian and Alaska Native communities, including white papers on review of research studies, data control options, and genetics research. The PRC also has a publication called [“Walk Softly and Listen Carefully”: Building Research Relationships with Tribal Communities](#), a collaboration between the PRC and Montana State University.



In addition, these resources may be of value:

- ◇ **Tribal Nations Research Group** (<https://tnrg.org/>) promotes high quality research relevant to the Turtle Mountain Band of Chippewa Indians. The research results provide custom fit data and data ownership, promotes public and private economic development and opportunity, and upholds positive images of Turtle Mountain Band of Chippewa Indians. The TNRG also provides quality research education materials designed to educate the community about research and the research process, according to the standards established by the TNRG.
- ◇ **Native Research Network (NRN)** (<https://www.nativeresearchnetwork.org/>) advocates for high quality research that is collaborative, supportive, and builds capacity. NRN promotes an environment for research that operates on the principles of integrity, respect, trust, ethics, cooperation, and open communication in multi-disciplinary fields.
- ◇ **Center for Rural Health, University of North Dakota** (<https://ruralhealth.und.edu/>) works with tribal communities to help improve health outcomes and well-being for American Indians, specifically geared toward helping Elders.

The following links provide more information about how some tribal governments have structured their IRBs and research protocols:

- ◇ **Cherokee Nation IRB:** <https://irb.cherokee.org>
- ◇ **Indian Health Service (IHS):** <https://www.ihs.gov/dper/>
- ◇ **Navajo Nation Research Review Board:** <https://www.nnhrrb.navajo-nsn.gov/aboutNNHRRB.html>
- ◇ **Rocky Mountain Tribal Institutional Review Board:** <https://www.rmtlc.org/rocky-mountain-tribal-institutional-review-board/>
- ◇ **Southwest Tribal IRB:** <https://www.aaihb.org/southwest-tribal-institutional-review-board/>

Please also download our companion pocket guide, [Understanding Tribal Sovereignty: Seeking approval for prevention and research efforts](#), or order print copies by emailing cph-nativecenter@uiowa.edu.

Additional Resources

<p>The Collaborative Research Center for American Indian Health (CRCAIH)</p>	<p>CRCAIH Tribal IRB Toolkit</p> <p>CRCAIH Research Data Management Toolkit Version 2.0</p>
<p>Native American Center for Excellence Substance Use Prevention</p>	<p>Steps for Conducting Research and Evaluation in Native Communities</p>
<p>The Partnership for Native American Cancer Prevention</p>	<p>How to Conduct Research in American Indian and Alaska Native Communities</p>
<p>Seattle Indian Health Board – Urban Indian Health Institute</p>	<p>Best Practices for American Indian and Alaska Native Data Collection</p>
<p>UNM Department of Psychiatry Center for Rural and Community Behavioral Health</p>	<p>Guiding Principles for Engaging in Research with Native American Communities</p>



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Research at the Speed of Trust:

A guide for researchers and Native communities



National American Indian & Alaska Native

PTTC

Prevention Technology Transfer Center Network

Funded by Substance Abuse and Mental Health Services Administration

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