



NATIONAL CONGRESS OF AMERICAN INDIANS

POLICY RESEARCH CENTER

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Research Policy Update
Frequently Asked Questions (FAQs):
Partnering with Tribal Nations on Research

The purpose of this update is to provide answers to frequently asked questions from those interested in partnering on research studies with Tribal Nations. These answers are intended as general advice, and researchers should work directly with Tribal Nations and understand and follow their priorities, laws, policies, and research oversight mechanisms.

Frequently Asked Questions (FAQs)
Partnering with Tribal Nations on Research

1. How do I partner with a Tribal Nation on research?

Tribal Nations are sovereign nations and have control over their citizens, lands, and resources. Tribal Nations have the right to control any research that occurs on their lands, about their resources, or with their citizens and may have had negative experiences with researchers in the past. As a result, you cannot conduct research with a Tribal Nation unless you have their approval. This approval must happen in the official tribal process, which could include tribal council approval, tribal Institutional Review Board (IRB) approval, or a designated office/committee/other IRB approval. You cannot start research with the approval of staff from a tribal program; the official tribal government must also approve research. You must learn if the Tribal Nation is willing to partner on research and their conditions, requirements, and laws. The Tribal Nation may not want to have any research conducted in your area of interest, so it is important to listen and learn about the priorities of the Tribal Nation. Research conducted with Tribal Nations must be done in partnership, must respect their sovereign status, and must protect and benefit the community.

2. Are Tribal Nations interested in partnering with researchers on research projects?

It depends on the research project and the Tribal Nation. Tribal Nations understand the importance of research and data, and many do have successful collaborations with researchers.

However, they may not be interested in working on a research project that is not a priority for their community, they may be wary of researchers due to past negative experiences, or they may be focused on other priorities and don't have time. The only way you will know if a Tribal Nation is willing to partner with you on a research project is to request time to meet with them and understand their priorities and review processes.

3. If I have university or other IRB approval, can I conduct my research with a Tribal Nation?

Not yet. You cannot conduct research with a Tribal Nation without their approval, no matter how many other IRB approvals you may have. Tribal Nations are sovereign and have control over their citizens, lands, and resources. Tribal Nations have the right to control any research that occurs on their lands, about their resources or with their citizens. You can only conduct research that is approved by the Tribal Nation according to their specific research review and approval processes, which vary by Tribal Nation. They might require tribal council approval, committee approval, tribal research review or IRB approval, or may delegate the approval to another IRB, including regional IRBs that serve many Tribal Nations. The Common Rule allows Tribal Nations to require their own research review even if there is a designated Single IRB.

4. What IRB approvals do I need to conduct research in an Indian Health Service (IHS) or tribal facility?

You likely need several IRB approvals, including your own institution's requirements, the IHS Area and/or National IRB, and relevant local IRBs or approvals from the Tribal Nations served by the facility. If you are recruiting at an IHS facility or using IHS medical records, you definitely need IHS IRB approvals, in addition to any relevant tribal approvals. The IHS National IRB can help answer your questions about what approvals are necessary. For more information on IHS IRBs, visit: <https://www.ihs.gov/dper/research/hsrp/instreviewboards/>.

5. Is there a difference between IRB approval and tribal approval?

Tribal Nations can establish their own IRBs, but they all have the right to tribal approval of research. Tribal approval relates to whether the Tribal Nation approves of the research, and often includes IRB approval, but can also include whether the project is a priority of the community and requirements beyond the usual requirements of the IRB.

6. Can I publish research results from a project with a Tribal Nation?

It depends. Have you gotten approval from the Tribal Nation? Tribal Nations are sovereign nations and researchers should always get approval for publishing any results or even any information about a research project. Tribal Nations have experienced negative outcomes as a result of the publication of research results that they did not approve or interpretations of that research that negatively impacted their communities.

7. I have data from a past project with a Tribal Nation. Can I use that information in a new research project?

No. You need approval of the Tribal Nation for any use of that data beyond the original approval when thinking of using data you have or data from another researcher.

8. I want to do research in an urban area with a significant number of American Indians and Alaska Natives (AI/ANs). What approvals do I need?

Given the sensitive nature of research with AI/ANs and Tribal Nations, you must take extra care to figure out what approvals are needed by asking the local community. If there is an urban Indian health organization or AI/AN organization, they can let you know the local practice. They also may be able to let you know about whether the Tribal Nations in the region would also require tribal approval. If you plan to use the tribal affiliation of the participants or a Tribal Nation is somehow identified, then you likely need Tribal Nation approval. If you are conducting the research with an IHS, tribal, or urban Indian health facility, IHS IRB review is required, and you must also comply with HIPAA, privacy rules, etc. The only way to know is to ask and to take the same care in making sure you are getting the right approvals for both rural and urban AI/ANs and Tribal Nations.

For more information on IHS IRBs, visit:

<https://www.ihs.gov/dper/research/hsrp/instreviewboards/>.

9. I want to conduct an online survey with AI/ANs as my respondents. Do I need to seek any type of reviews/approvals other than my institution's IRB?

This is a new area where there are differing opinions. Of course, this type of survey or polling is complicated because you cannot be sure that the person answering the survey is actually AI/AN even if you ask that question. As a result, the quality of the research is likely to be doubted, and its potential to cause harm is increased. If this is research, then all the appropriate IRB approvals are needed to make sure to protect and benefit the individual participants and their communities, including any Tribal Nations that may be impacted. If this is not research (such as an evaluation of a program that won't be published and only used internally to improve the program), care still needs to be taken because of the always present risk of harm to AI/ANs and Tribal Nations. If a researcher has a need to gather information about tribal affiliation, the risk of the activity, research or not, is increased and many Tribal Nations would require approval for their tribal name to be used. It is possible that even a survey that is anonymous and does not ask about tribal affiliation could harm a Tribal Nation or AI/ANs depending on the content of the questions or the potential results. In general, care needs to be taken to consider the appropriate approvals and reviews and to do everything to ensure that human subjects, AI/ANs, and Tribal Nations are protected and benefit from the research.

10. We worked on a research project with a Tribal Nation and want to publish a press release on the exciting results. Someone said we should let the Tribal Nation know about the press release. Do we need their approval?

Yes, you need the Tribal Nation's approval for any public release of the results, including publications, presentations, or press releases. You should not publish or make public any research results unless you have reviewed the exact way you will present the results and any actual publications, presentation notes or PowerPoints, or press releases with the Tribal Nation(s) involved for their approval. Harmful outcomes have occurred when researchers publish results without letting the involved Tribal Nation(s) review and approve the information intended to be shared. Most Tribal Nations will likely say they require publication or review of results, but even if they don't, they are sovereign nations and deserve to review and approve any reporting of results. They likely will have important information to share in terms of the interpretation and potential impacts of the data, and by working with them before release of the results, you are potentially avoiding any mistakes, inaccurate or inappropriate conclusions, or harmful statements. This is the most common adverse outcome of research done with Tribal Nations – always gain approval for any public statements about the research. Failing to do so is a violation of the research partnership.

11. I asked a Tribal Nation to work on a research project with me, but they did not respond or refused. What options do I have? This research is really important.

While this research may be important to you, it may not be a priority to the Tribal Nation, or they may be too busy to work with you. They are a sovereign nation, and they can decide whether to work with you or not. You don't have any other options – their word is final. You could consider re-engaging them in the future after you have learned more about the Tribal Nation and their priorities, but they could still refuse to work with you. It is their choice, and if they do agree to partner with you on research, it is a privilege to work with a Tribal Nation on a research project.

12. I want to work with a Tribal Nation on a research project, but they said that I needed to pay them to have their IRB review the project and that at least 30 percent of my research grant budget should go to them. Can they make these demands?

Yes, they can make these types of requirements. They are a sovereign nation, and they can ask you to do whatever they feel is appropriate to make the research worth their time. Often, Tribal Nations are taken advantage of by researchers who are the only ones who benefit from the research through career advancement and publications. It is now expected that researchers consider the work with a Tribal Nation a partnership and that they consider how the research can benefit the community, such as including paying for tribal staff to participate in the project to develop local capacity for research. Tribal IRBs also can charge a fee for proposal review to help support their IRB review process. Since Tribal Nations are partners in the research, they need to be funded to participate as you would fund any other partner and should benefit from the research from their viewpoint.

13. If the Tribal Nation agrees to the research project, do we still have to ask people in the community if they want to participate?

Yes. Even if the Tribal Nation agrees to participate in the research project, researchers still have an obligation to conduct informed consent for individuals to ensure that they know what the project is and that their participation is voluntary. How you recruit individuals needs to be a part of the IRB review and tribal approval before starting the project. In addition, recruitment cannot occur before review and approval.

14. Since Tribal Nations are sovereign nations, do the principles of the Belmont Report apply?

Yes. Tribal Nations are sovereign nations, but the Belmont Report applies to any research that is conducted with human subjects. Researchers must prove to IRBs that they are complying with ethical principles and guidelines for research involving human subjects, including how they address the three basic principles in the Belmont Report: respect for persons, beneficence, and justice. All these principles apply to individuals (human subjects in research) and to research conducted with Tribal Nations.

15. Can we use the same recruitment materials with AI/ANs as we use for other racial/ethnic groups?

It depends. Recruitment materials must be approved by the IRB and any other research review including approvals by Tribal Nations. During this process, researchers must demonstrate that these recruitment materials are ethically appropriate, meet any IRB requirements, and also are appropriate to the local community, including their culture and language. Recruitment cannot begin until all IRB and research review steps are completed and the materials are deemed to be appropriate and consistent with ethical principles of research and appropriate for the local community.

16. How much should we pay AI/AN participants for completing our survey?

An appropriate amount can be discussed with the local community and the IRB/research review group. The amount should be enough to compensate their time, but not too much to be coercive to a vulnerable population. Care must be taken in communities with high unemployment or economic hardships.

17. My university IRB determined that my research project with the Tribal Nation is exempt from IRB review. Do I have to go through the tribal research review process?

Yes. Many Tribal Nations do not have an exempt category in their IRB or research review processes. They may consider that any data collection requires tribal review. You must ask the Tribal Nation about their review processes and comply even if you have already completed IRB review with an external IRB.

18. My research project with the Tribal Nation generated a large dataset that I would like to share with my research collaborators. Do I have to ask the Tribal Nation for permission?

Yes, you must ask for permission and review of any research that is above and beyond the original approval you received from the Tribal Nation. The Tribal Nation approval was only for the original project and not for secondary analysis of the data. Many adverse outcomes have occurred when researchers used data beyond what the Tribal Nation approved, and using the data for other research without approval is a very serious violation of the agreement and may result in you or your institution having legal action taken against them and having to pay large fines or settlements.

19. My research project had some interesting and unexpected results, and I realize that we can take the results and develop a therapy for profit. Do we need to involve the Tribal Nation in this work that occurs after the approved research project is done?

Yes. You must include the Tribal Nation in any for profit activities that result from the research since it is likely that the Tribal Nation owns the intellectual property rights to the data and any inventions that result from the research. Even if this was not in the original agreement or a written requirement, it would be ethically wrong to use these results to personally benefit and not allow the Tribal Nation the ability to claim intellectual property rights and to benefit from an invention from the research. Tribal Nations are sovereign nations, and they have the rights to control anything that happens with their citizens, lands, and resources.

20. We wrote a research grant application to conduct research with the local Tribal Nation and got funded. However, the Tribal Nation claims we did not get approval, but we talked to a program staff when we were writing the grant. If we don't do this research, we will lose the funding. Can we just proceed since someone from the Tribal Nation approved it?

No, you must have approval of the Tribal Nation i.e. the government of the Tribal Nation to conduct research via their official process. Unless the Tribal Nation expressly delegated approval of research to this program staff person, you cannot conduct the research. It doesn't matter whether you received funding or you are worrying that you will lose it. Unless the Tribal Nation approved it, you cannot conduct the research. Research grant applications should not be submitted without all relevant approvals, including approvals from Tribal Nations and if relevant, the IHS National and regional IRBs.

21. We found out about a great funding opportunity but the deadline is in 2 weeks. We don't really have time to seek other IRB approvals or to talk with the Tribal Nation we want to work with. Can we submit the application and then get all the approvals later.

No. While NIH allows "just in time" submissions for IRB approvals before you get funded, it is considered bad practice and is potentially unethical to submit a research grant application that involves a sovereign Tribal Nation without getting their approval first. The deadline issue is your

issue, not the Tribal Nation's issue. NIH reviewers and staff are also now being taught that a grant application that mentions a Tribal Nation that has no evidence of tribal approval is not appropriate.

22. What happens if I violate a Tribal Nation's research oversight policies or laws?

Researchers should do everything they can to follow a Tribal Nation's research oversight policies and laws, because they may be subject to fines or other punishment as indicated by these laws or policies. The Common Rule says that Tribal Nations can establish research laws that federally funded researchers must follow, and they can make those laws stricter than what is required by federal regulations.

23. Our collaborative research project has a Single IRB, so our project leader says we don't have to get IRB approval from the Tribal Nation. Is this true?

No, the Common Rule says that there is an exception to the Single IRB requirement for Tribal Nations, which means the Tribal Nation can require that the project is reviewed by their IRB or research review process.

24. Given all these issues, is it worth it to partner with Tribal Nations on research projects?

We think it is worth it to partner with Tribal Nations on research. While there are different considerations and requirements for partnering on research with Tribal Nations, the benefits to the community can be significant, especially if the research is conducted in a respectful and ethical manner with the full approval and participation of the Tribal Nation.

25. I am worried that I won't get promoted if I work with Tribal Nations on research since it seems to take longer than other types of research.

The Tribal Nation likely is not concerned with whether you get promoted or not. This type of research does take more time to respectfully work with Tribal Nations, and some academic centers are starting to realize the time commitment in their promotion and tenure reviews. You may want to work on other research that is not as time consuming to help build your portfolio to advance your career.

26. Where can I get more information about working with Tribal Nations on research?

Researchers should make extra effort to learn about working with Tribal Nations on research generally and should make extra effort to learn about working with a specific Tribal Nation. The list of references at the end of this document is only a selection of the wide variety of resources on this topic that have been developed over the past couple of decades. Researchers can no longer claim that they did not know about these issues, and learning about how to respectfully conduct research with Tribal Nations is now an expected part of the research process. While the

information in this FAQ document is intended to be general information, researchers must contact each Tribal Nation for their specific requirements.

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Questions: For more information, email the NCAI Policy Research Center at research@ncai.org.

Resources – NCAI Policy Research Center

NCAI Policy Research Center – Research Policy Updates on the Common Rule: <http://bit.ly/2P8Xnu6>

NCAI Policy Research Center (2019). Research Policy Update: Intellectual Property Rights and Tribal Nations. National Congress of American Indians, October 2019: <http://bit.ly/2Bp42en>

NCAI Policy Research Center and MSU Center for Native Health Partnerships (2012). “Walk Softly and Listen Carefully:” Building research relationships with tribal communities. Washington, DC and Bozeman MT: Authors: <https://bit.ly/3H4Xn9N>

NCAI Policy Research Center (2018). The State of Tribal Data Capacity in Indian Country: Key Findings from the Survey of Tribal Data Practices. Washington, D.C. National Congress of American Indians: <http://bit.ly/2T8hU43>

Collaborative Research Center for American Indian Health – NCAI Policy Research Center Research Ethics (CRCAIH) webpage resources: <https://bit.ly/3qj986v>

Holding Space: A Guide for Partners in Tribal Research. NCAI Policy Research Center/University of Nevada Reno webpage resources - <https://bit.ly/3qfqlxJ>

Federal Resources:

Indian Health Service Research Program: <https://www.ihs.gov/dper/research/>;
Human Subjects Research Protections: <https://www.ihs.gov/dper/research/hsrp/>;
IRBs: <https://www.ihs.gov/dper/research/hsrp/instreviewboards/>

HHS Office for Human Research Protections (OHRP): <https://www.hhs.gov/ohrp/index.html>

National Institutes of Health Tribal Health Research Office (THRO): <https://dpcpsi.nih.gov/thro>

National Institutes of Health/National Institute of General Medical Sciences - Native American Research Centers for Health: <https://www.nigms.nih.gov/Research/DRCB/NARCH/Pages/default.aspx>

Selected Publications in Alphabetical Order:

American Indian and Alaska Native Research in the Health Sciences:

Critical Considerations for the Review of Research Applications. National Institutes of Health, 2020. https://dpcpsi.nih.gov/sites/default/files/Critical_Considerations_for_Reviewing_AIAN_Research_508.pdf

Around Him D, Aguilar TA, Frederick A, Larsen H, Seiber M, Angal J (2019). Tribal IRBs: A Framework for Understanding Research Oversight in American Indian and Alaska Native Communities. *Am Indian Alask Native Ment Health Res.* 2019; 26(2): 71095.

DOI: <https://doi.org/10.5820/aian.2602.2019.71>

Blacksher E, Nelson C, Van Dyke E, Echo-Hawk A, Bassett D, Buchwald D. Conservations about Community-Based Participatory Research and Trust: "We are Explorers Together." *Prog Community Health Partnersh.* 2016; 10(2): 305-9. DOI: <https://doi.org/10.1353/cpr.2016.0039>

James RD, West KM, Claw KG, EchoHawk A, Dodge L, Dominguez A, Taulii M, Forquera A, Thummel K, Burke W (2018). Responsible Research with Urban American Indians and Alaska Natives. *Am J Public Health* 2018 Dec; 108(21): 1613-1616. DOI: <https://doi.org/10.2105/ajph.2018.304708>

Kuhn NS, Parker M, Lefthand-Begay C (2020). Indigenous Research Ethics Requirements: An Examination of Six Tribal Institutional Review Board Applications and Processes in the United States. *J Empir Res Hum Res Ethics.* 2020 Oct; 15(4): 279-291. DOI: <https://doi.org/10.1177/1556264620912103>

Lucero JE, Emerson AD, Beurle D, Roubideaux Y (2020). The Holding Space: A Guide for Partners in Tribal Research. *Prog Community Health Partnersh.* 2020;14(1): 101-107. DOI: <https://doi.org/10.1353/cpr.2020.0012>

Lucero JE, Roubideaux Y (2020). Holding Space for All of Us. *AMA J Ethics.* 2020 Oct 1; 22(10):E882-887. DOI: <https://doi.org/10.1001/amajethics.2020.882>

Saunkeah B, Beans JA, Percy MT, Hiratsuka V, Spicer P. Extending Research Protections to Tribal Communities. *Am J Bioeth* 2021 Oct; 21(10): 5-12. DOI: <https://doi.org/10.1080/15265161.2020.1865477>