



University of Colorado
Anschutz Medical Campus

“Nothing About Us Without Us”: Meaningful Engagement of Tribal Communities in Research

Spero M. Manson, PhD

Centers for American Indian and Alaska Native Health

Presidents Ronald Reagan and George W.H. Bush



American Indian Policy

On January 24, 1983, President Ronald Reagan issued an American Indian policy statement which reaffirmed the government-to-government relationship of Indian tribes with the United States; expressed the primary role of tribal governments in reservation affairs; and called for special efforts to develop reservation economies.

The President's policy expanded and developed the 1970 national Indian policy of self-determination for Indian tribes. President Reagan said it was the goal of his administration to turn the ideals of the self-determination policy into reality. President Reagan's policy statement follows.

This Administration believes that responsibilities and resources should be restored to the governments which are closest to the people served. This philosophy applies not only to state and local governments, but also to federally recognized American Indian tribes.

When European colonial powers began to explore and colonize this land, they entered into treaties with sovereign Indian nations. Our new nation continued to make treaties and to deal with Indian tribes on a government-to-government basis. Throughout our history, despite periods of conflict and shifting national policies in Indian affairs, the government-to-government relationship between the United States and Indian tribes has endured. The Constitution, treaties, laws, and court decisions have consistently recognized a unique political relationship between Indian tribes and the United States which this Administration pledges to uphold.

In 1970, President Nixon announced a national policy of self-determination for Indian tribes. At the heart of the new policy was commitment by the federal government to foster and encourage tribal self-government. That commitment was signed into law in 1975 as the Indian Self-Determination and Education Assistance Act.

The principle of self-government set forth in this Act was a good starting point. However, since 1975, there has been more rhetoric than action. Instead of fostering and encouraging self-government, federal policies have by and large inhibited the political and economic development of the tribes. Excessive regulation and self-perpetuating bureaucracy have stifled local decisionmaking, thwarted Indian control of Indian resources, and promoted dependency rather than self-sufficiency.

This Administration intends to reverse this trend by removing the obstacles to self-government and by creating a more favorable environment for the development of healthy reservation economies. Tribal governments, the federal government, and the private sector will all have a role. This Administration will take a flexible approach which recognizes the diversity among tribes and the right of each tribe to set its own priorities and goals. Change will not happen overnight. Development will be charted by the tribes, not the federal government.



This Administration honors the commitment this nation made in 1970 and 1975 to strengthen tribal governments and lessen federal control over tribal governmental affairs. This Administration is determined to turn these goals into reality. Our policy is to reaffirm dealing with Indian tribes on a government-to-government basis and to pursue the policy of self-government for Indian tribes without threatening termination.

In support of our policy, we shall continue to fulfill the federal trust responsibility for the physical and financial resources we hold in trust for the tribes and their members. The fulfillment of this unique responsibility will be accomplished in accordance with the highest standards.

Tribal Self-Government

Tribal governments, like state and local governments, are more aware of the needs and desires of their citizens than is the federal government and should, therefore, have the primary responsibility for meeting those needs. The only effective way for Indian reservations to develop is through tribal governments which are responsive and accountable to their members.

Early in this nation's dealings with Indian tribes, federal employees began to perform Indian tribal government functions. Despite the Indian Self-Determination Act, major tribal government functions—enforcing tribal laws, developing and managing tribal resources, providing health and social

For Immediate Release

June 14, 1991

STATEMENT BY THE PRESIDENT

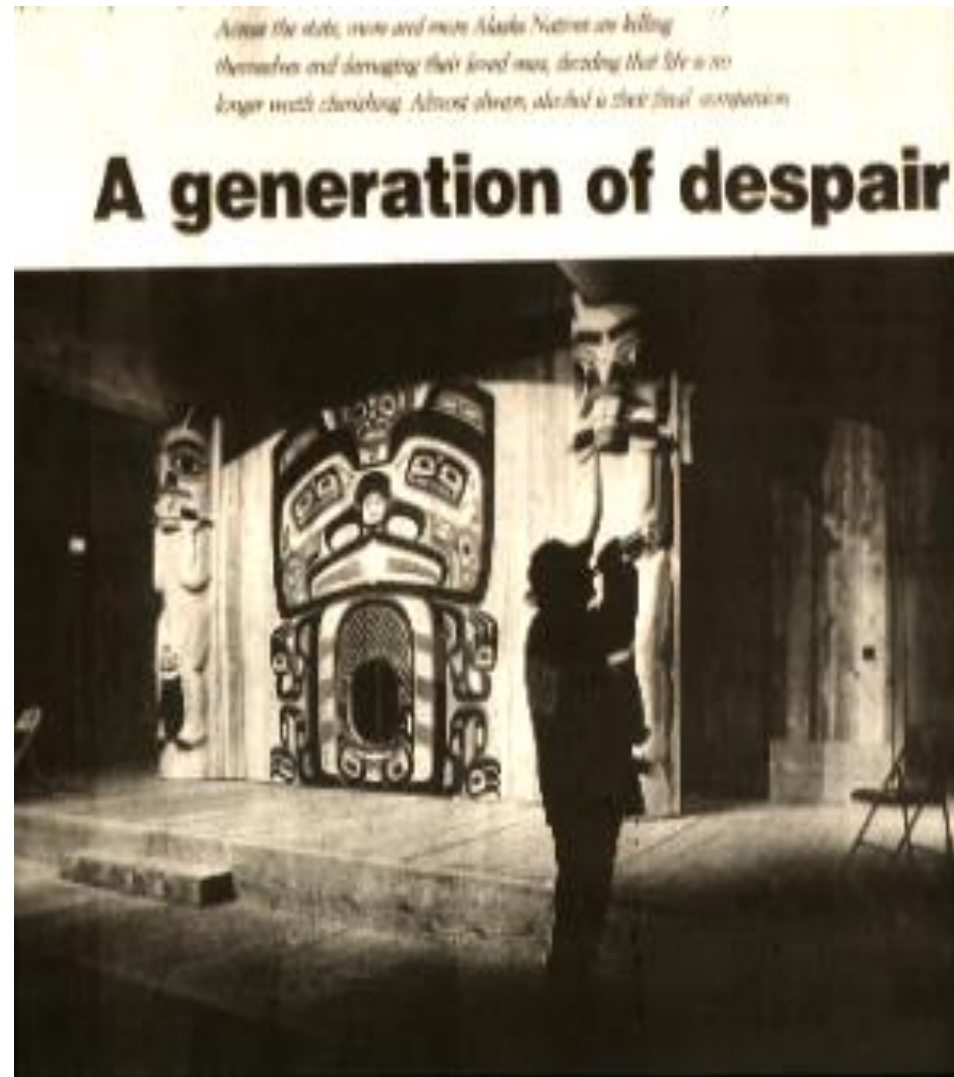
REAFFIRMING THE GOVERNMENT-TO-GOVERNMENT RELATIONSHIP BETWEEN THE FEDERAL GOVERNMENT AND TRIBAL GOVERNMENTS

On January 24, 1983, the Reagan-Bush Administration issued a statement on Indian Policy recognizing and reaffirming a government-to-government relationship between Indian tribes and the Federal Government. This relationship is the cornerstone of the Bush-Quayle Administration's policy of fostering tribal self-government and self-determination.

Barrow Alcohol Study

Report entitled “The Inupiat, Economics and Alcohol on the Alaskan North Slope” released simultaneously to the press and to the Barrow community. January 22, 1980, New York Times, ran a front page story entitled “Alcohol Plagues Eskimos”

“The Inupiat Eskimos of Alaska’s North Slope, whose culture has been overwhelmed by energy development activities, are ‘practically committing suicide’ by mass alcoholism...”



“Alcohol Plagues Eskimos”

New York Times

“The alcoholism rate is 72 percent among the 2,000 Eskimo men and women in the village of Barrow, where violence is becoming the most frequent cause of death as a result of ‘the explosive and self-destructive abuse of alcohol ...’

‘Offshore oil development is expected to peak in 2010 or 2015’
‘We don’t see the Eskimos surviving till then. This is not a collection of individual alcoholics, but a society which is alcoholic, and therefore facing extinction.’”



Havasupai Tribe vs. Arizona State University



Troubled by the increase in the number of diabetes cases among their members, the Havasupai Tribe, in 1989, agreed to let researchers from Arizona State University draw and test their blood to try to find a reason for the elevated rate of the disease. When a paper on the research was published in 1991 stating there was no genetic reason for the high levels of diabetes, the tribe thought that was that.

“Arizona’s Broken Arrow: Did Arizona State University Genetically Rape the Havasupai Tribe?”

Phoenix Magazine



However, Arizona State University continued using the samples for more research, according to an article in *Native Peoples*. “Unbeknownst to the tribe,” writes Patty Talahongva, “additional research using the samples went on for more than a decade.” “[I]nstead of using that blood solely for diabetes research [ASU staff members] conducted further research, on schizophrenia, inbreeding and even migration patterns.

President William Clinton

Executive Order 13084

Executive Order 13084

by *President of the United States*

Consultation and Coordination With Indian Tribal Governments

[◀ Executive Order 13083](#)

[Executive Order 13085 ▶](#)

Signed by President [William J. Clinton](#) Thursday, May 14, 1998

Federal Register page & date: 63 [FR 27655](#), Tuesday, May 19, 1998

Executive Memorandum of April 29, 1994

Memorandum of April 29, 1994

[Federal Register: May 4, 1994]

Presidential Documents

Federal Register

Vol. 59, No. 85

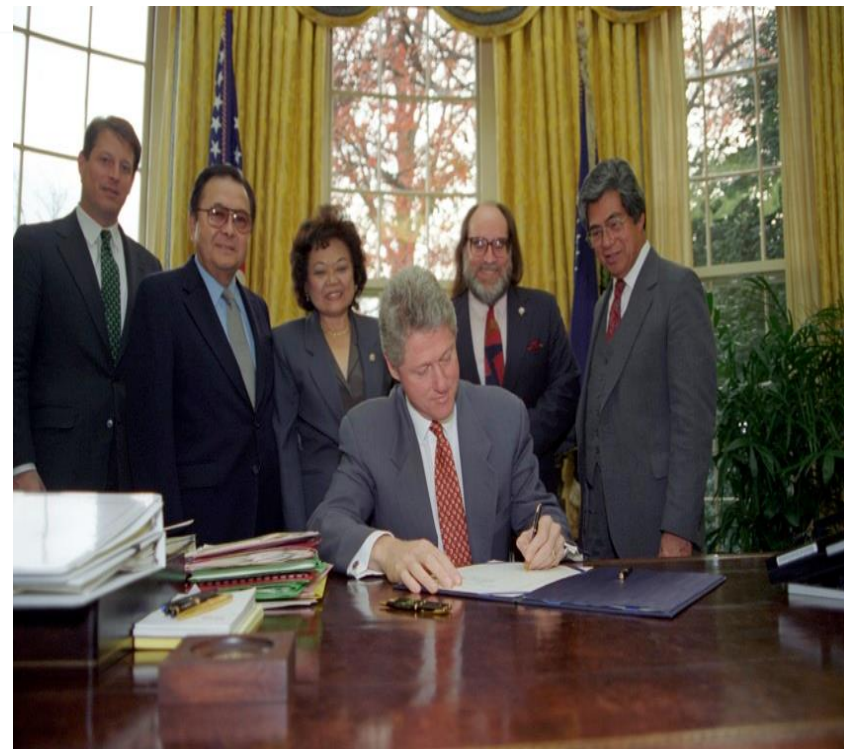
Title 3-

The President

Memorandum of April 29, 1994

Government-to-Government Relations With Native
American Tribal Governments

Memorandum for the Heads of Executive Departments and
Agencies



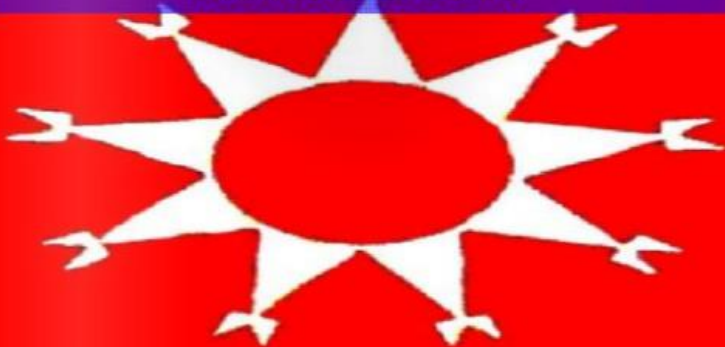
Tribal and Indian Health Service Institutional Review Boards

Navajo Nation | Navajo Nation Department of Health | Navajo Nation Human Research Review Board

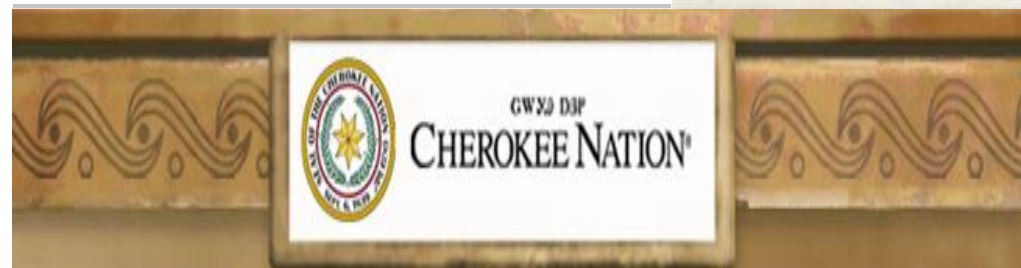
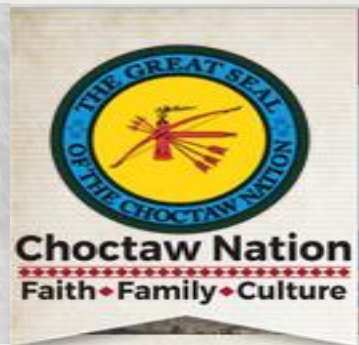
Navajo Nation Human Research Review Board

CHOCTAW INSTITUTIONAL REVIEW BOARD SAFEGUARDS THE NATION'S INTERESTS IN RESEARCH

Oglala Sioux Tribal Research
Review Board



Exercising our Sovereignty



President George W. Bush

Administration of George W. Bush, 2004 / Sept. 23

Memorandum on Government-to-Government Relationship With Tribal Governments September 23, 2004

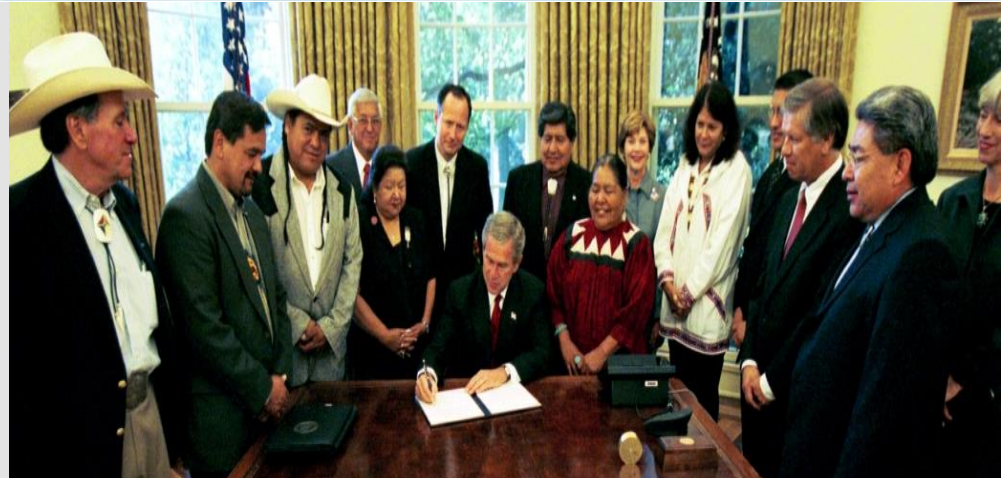
Memorandum for the Heads of Executive Departments and Agencies

Subject: Government-to-Government Relationship with Tribal Governments

The United States has a unique legal and political relationship with Indian tribes and a special relationship with Alaska Native entities as provided in the Constitution of the United States, treaties, and Federal statutes. Presidents for decades have recognized this relationship. President Nixon announced a national policy of self-determination for Indian tribes in 1970. More recently, Executive Order 13175, entitled Consultation and Coordination with Indian Tribal Governments, was issued in 2000. I reiterated my Administration's adherence to a government-to-government relationship and support for tribal sovereignty and self-

mental Affairs serves as my White House liaison with all Indian nations and works with federally recognized tribal governments on an intergovernmental basis. Moreover, it is critical that all departments and agencies adhere to these principles and work with tribal governments in a manner that cultivates mutual respect and fosters greater understanding to reinforce these principles.

Accordingly, the head of each executive department and agency (agency) shall continue to ensure to the greatest extent practicable and as permitted by United States law that the agency's working relationship with federally recognized tribal governments fully respects the rights of self-government and self-determination due tribal governments. Department or agency inquir-



President Barak Obama

The White House

For Immediate Release

November 05, 2009

Presidential Memorandum on Tribal Consultation

THE WHITE HOUSE

Office of the Press Secretary

For Immediate
Release

November 5, 2009

**MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS
AND AGENCIES**



U.S. Department of Health and Human Services

U. S DEPARTMENT OF HEALTH AND HUMAN SERVICES TRIBAL CONSULTATION POLICY

Kathleen Sebelius
Secretary
U.S. Department of Health and Human Services

Date

12/14/10

National Institutes of Health Guidance on the Implementation of the HHS Tribal
Consultation Policy

Tribal Health Research Office



Tribal Support

[CDC](#) > [STLT Gateway Home](#) > [Tribal Support](#)

CDC/ATSDR Tribal Consultation



[Tribal Consultation Policy](#)

Government-to-government consultation will be conducted before making decisions that affect them. CDC's Tribal Consultation designees, with opportunities to interact with CDC lead

[Biannual Tribal Consultation Sessions](#)

These sessions are attended by elected tribal leaders, or one is hosted by a tribe or area tribal health board in and

[HHS Tribal Consultation](#)

CDC participates in annual HHS national and regional tr

Handbook for Consultation With
Federally-Recognized Indian Tribes

Issued December 2011



The Search for Common Ground: Organizational Differences

Organizational, political, and cultural differences among tribal communities, investigators, and research sponsors complicate the search for common ground

In universities and the federal government ...

- ◆ decision-making is hierarchical and rule-driven
- ◆ process emphasizes efficiency, replicability, and written documentation
- ◆ leadership is formal and centralized, often context-free
- ◆ analytic thinking is prominent, assume an answer
- ◆ instrumental competence is highly valued, and standard for assessment

In tribal communities

- ◆ decision-making is horizontal, precedent-oriented, and consensual
- ◆ process is fluid, iterative, recorded orally, benchmarked by key events
- ◆ leadership is shared, diffused, and ascribed rather than attributed
- ◆ emphasis is on distributive cognition, assume multiple answers
- ◆ authority is rooted in collective competence

The Search for Common Ground: Political Differences

In universities and the federal government ...

- ◆ representation is of a collective of individuals, of constituents
- ◆ objective is to govern or to control individuals, groups thereof
- ◆ competence stems from delegated authority, administrative license
- ◆ accountability couched in terms of blameworthiness, liability
- ◆ obedience through instruction and compliance

In tribal communities

- ◆ representation is of an individual collective, of a body politic
- ◆ objective is to manage interdependent relationships
- ◆ authority is rooted in moral and social responsibility
- ◆ accountability framed as obligation to and acceptance by others
- ◆ conformity through adherence to shared values

The Search for Common Ground: Cultural Differences

The non-tribal world tends to ...

- ◆ be person-centric
- ◆ prize privacy and anonymity
- ◆ emphasize majority opinion
- ◆ be goal-directed, value problem-solving
- ◆ perceive time as a commodity, limited, and to be managed

Tribal communities tend to

- ◆ be sociocentric
- ◆ seek cooperation, de-emphasize conflict
- ◆ stress mutuality, belonging, solidarity
- ◆ tolerate differences
- ◆ encourage common vision, shared principles
- ◆ be cautious, deliberate, and patient, assume that events unfold

Points of Tension: Enacting the Belmont Report

Respect for Persons

This principle emphasizes the concept that individuals are “autonomous agents” capable of “self-determination.” It also means that individuals should not be coerced into participating in research, and their decisions regarding research participation should be respected.

Beneficence

This principle means that researchers have the “obligation” to not harm research volunteers and to maximize possible benefits while minimizing possible harms of the research.

Justice

This principle states that the burdens of research should be equally distributed amongst different groups, including individuals of different racial and socioeconomic backgrounds. The fairness demanded by this principle also means that “research supported by public funds” must ensure that the benefits of the research, such as new drugs or diagnostic tests, are equally available to all individuals, even those considered socially disadvantaged.

Points of Tension: Practical Matters

- ◆ Review and approval of research
- ◆ Distribution of resources
- ◆ Manner of informed consent
- ◆ Nature and extent of accountability and control
- ◆ Data ownership and sharing
- ◆ Requirements for continued collaboration

Emerging Solutions: Recent Examples

Data Sharing Agreement

for the

**Native Center for Alcohol Research and Education: Transition
to Recovery NIAAA Grant # 1P60AA026112
U54MD011240**

between

Fairbanks Native Association

and the

Washington State University

This Data Sharing Agreement ("Agreement") is made by and between Washington State University ("Recipient" or "WSU") and Fairbanks Native Association ("Covered Entity" or "FNA") effective July 1, 2018 ("Effective Date").

The purpose of this Agreement is to establish the data sharing relationship of de-identified data for the purposes of scientific research under Research Subaward 5388 (Buchwald, Dedra to Manson, Spero M., University of Colorado Anschutz medical Campus; Transition to Recovery) ("Underlying Agreement").

MEMORANDUM OF AGREEMENT

between

SEATTLE INDIAN HEALTH BOARD

and

UNIVERSITY OF COLORADO ANSCHUTZ MEDICAL CAMPUS

This Data Sharing Agreement ("Agreement") is made and entered into by and between the Seattle Indian Health Board (SIHB, Covered Entity) and the University of Colorado – Anschutz Medical Campus, Centers for American Indian and Alaska Native Health (CAIANH, Recipient). The purpose of this Agreement is to establish the data sharing relationship of de-identified data acquired in the Screening, Brief Intervention, and Referral to Treatment (SBIRT) Evaluation phase of the scientific research under Research Grant 5U19 MH113135-02.

1. PROJECT PURPOSE AND SCOPE

1.1 **Project Purpose:** Covered Entity and Recipient are collaborating to plan, develop, and implement a research study about the prevention of American Indian and Alaska Native young adult suicide.

Data Sharing Agreement

for the

**Blood Pressure: Improving Control Among Alaska Native People
NIMHD Grant #U54MD011240**

between

Southcentral Foundation

and the

Washington State University

This Data Sharing Agreement ("Agreement") is made by and between Washington State University ("Recipient" or "WSU") and Southcentral Foundation ("Covered Entity" or "SCF") effective December 1, 2017 ("Effective Date").

The purpose of this Agreement is to establish the data sharing relationship of de-identified data for the purposes of scientific research under Research Subaward Agreement 127687 G003656 (SCF Contract Number 2016-165) ("Underlying Agreement").

Emerging Solutions: Recent Examples



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

National Institutes of Health
Bethesda, Maryland 20892

April 17, 2019

Dear Tribal Leader and Urban Indian Organization Leader:

I am writing to initiate a Tribal Consultation and an Urban Confer on provisions for the National Institutes of Health (NIH) draft policy on Data Sharing and Management for NIH Funded or Supported Research. We are seeking your input on key elements of how this policy should be drafted to support meaningful participation of Tribes in biomedical research. More specifically, how do Tribes define Scientific Data and what are the requirements for acceptable Data Sharing and Management Plans for proposed research with Tribal communities?

The NIH mission, achieved through research, research training, and the dissemination of research findings, is to seek fundamental knowledge about the nature and behavior of living systems and to apply that knowledge to enhance health, lengthen life, and reduce illness and disability. NIH has a responsibility to maintain stewardship over taxpayer funds by making the results and accomplishments of the research that it funds and conducts available to the public. In NIH's view, data should be made as widely and freely available as possible *while safeguarding the privacy of participants and protecting confidential and proprietary data.*

NIH Tribal Health Research Office

THRO Home TAC THRC Tribal Consultations Research and Funding Resources About Us

NIH Tribal Advisory Committee (TAC)



NIH Tribal Delegates & Advisors. Learn more »

NIH Tribal Advisory Committee (TAC)
The TAC is advisory to the NIH, and provides a forum for meetings between elected Tribal officials for their designated representatives and NIH officials to exchange views, share information, and seek advice concerning intergovernmental responsibilities related to the implementation and administration of NIH programs. (See our charter for more information.) It was established to help ensure that Tribes and AI/AN people have meaningful and timely input in the development of NIH policies, programs, and priorities. The NIH TAC seeks to ensure that NIH policies or activities that affect AI/AN communities are brought to the attention of Tribal Leaders.
Related Information
• Monthly Call Agendas
• Meetings
• Charter
• Members
The NIH TAC charter calls for representation from each of the 12 geographic areas served by the Indian Health Service (IHS) including Alaska, Albuquerque, Bemidji, Billings, California, Great Plains, Nashville, Navajo, Oklahoma, Phoenix, Portland, and Tucson. In addition, the NIH TAC charter calls for one representative (and a designated alternate) for each of five National at-large Tribal member positions. The NIH TAC met for the first time on September 29-30, 2015, and has met twice annually through September 2017.

NIH National Institutes of Health
Tribal Health Research Office

Search DPCPSI

THRO Home TAC THRC Tribal Consultations Research and Funding Resources About Us

Tribal Health Research Office (THRO)

The American Indian/Alaska Native (AI/AN) Research Grant Finder

Explore »

Navigation dots

Strategic Plan Portfolio Analysis **pdf** Grant Finder THRO News Stay Informed

Subscribe to the THRO listserv for the latest updates and news

DPCPSI » THRO

Emerging Solutions: Recent Examples

RESEARCH & DATA

OUR WORK

UPDATES

EVENTS

ABOUT PRC



NCAI Policy Research Center

Supporting Indian Country in Shaping its Own Future

Tribal Leader /
Scholar Forum

Trainings

Webinars

Videos / Playlists

Webinars

Upcoming Webinars & Teleconferences

Stay tuned for the next webinar in our Webinar Series - we will post the webinar topic and speaker soon!

Past Webinars

Click [HERE](#) to view the **NCAI Policy Research Center YouTube playlist**, featuring our past webinars and events. You can also view our webinars by clicking on the red links below.

Charting a Path Forward for Responsible Data Sharing. Our webinar in May 2019 featured speakers from the National Institutes of Health on their consultation with tribes on their work to develop a data sharing and management policy. View the NIH letter: <https://t.co/mo4GqeQsdg>

Intellectual Property Rights in Biomedical Research. Our webinar in March 2019 featured an overview from the National Institutes of Health (NIH) on the topic of Intellectual Property Rights in Biomedical Research. NIH is consulting with tribes on this important topic. View the NIH letter: bit.ly/2Pn8oZC

Considerations for Meaningful Collaboration with Tribal Populations

The Tribal Collaboration Working Group Report
to the *All of Us* Research Program Advisory Panel

April 4, 2018

Application of the 2023 NIH Data Management & Sharing Policy for American Indian and Alaska Native People

- January 2023, NIH issued a Data Management and Sharing (DMS) Policy to promote the sharing of scientific data to facilitated the development of treatments and programs to improve health. ^{1,2} NIH funded investigators are to: prospectively plan for the managing and sharing of scientific data, submit a DMS plan, and comply with the approved plan.
- NIH does not require that NIH-supported researchers who analyze data about American Indian and Alaska Native (AI/AN) people that has been generated by or in partnership with Tribal entities comply with the DMS Policy.
 - NIH recognizes the sovereignty of American Indian and Alaska Native Tribes and that compliance with this policy is optional.^{3,4,5,6}
 - NIH recommends that NIH-supported researchers work with Tribes to explore opportunities to share data that would benefit the health of their people.^{3,4}

¹ <https://oir.nih.gov/surcebook/intramural-program-oversight/intramural-data-sharing/2023-nih-data-management-sharing-policy>

² <https://sharing.nih.gov/data-management-and-sharing-policy>

³ Comments by the Advisory Committee to the NIH Director (Dr. Francis Collins), the NIH Interim Director (Dr. Lawrence Tabak), and the NIMHD Director (Dr. Eliseo Perez-Stable)

⁴ <https://dpcpsi.nih.gov/thro/tribal-consultations/draft-policy-for-data-management-and-sharing>

⁵ <https://sharing.nih.gov/faqs#/data-management-and-sharing-policy.htm?anchor=56549>

⁶ <https://grants.nih.gov/grants/guide/notice-files/NOT-OD-22-214.html>

Relevant Work

Norton IM, **Manson SM**. Research in American Indian and Alaska Native communities: Navigating the cultural universe of values and process. *J Consult Clin Psychol*. 1996;64(5), 856-860.

Manson SM, Garrouette EM, Goins RT, Nez Henderson P. Access, relevance and control in the research process: Lessons from Indian Country. *J Ag Health*. 2004;16(5S):58S-77S.

Moreno-John G, Gachie A, Fleming CM, Napoles-Springer A, Mutran E, **Manson SM**, Perez-Stable E. Ethnic minority older adults participating in clinical research: Developing trust. *J Ag Health*. 2004; 16(5S): 93S-123S.

Noe TD, **Manson SM**, Croy C, McGough H, Henderson JA, Buchwald DS. The influence of community-based participatory research principles on the likelihood of participation in health research in American Indian communities. *Eth Dis*. 2007;17: S1-14.

Goins RT, Garrouette EM, Leading S, Geiger SD, **Manson SM**. Theory and practice in participatory research: Lessons from the Native Elder Care Study. *Geront*. 2011; 51(3):285-94.