

At the Speed of Trust: Building Tribal and Federal Relationships in Health Research

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Alaska Indigenous Research Program May 13, 2022



What Does It Mean to Move at the Speed of Trust?

Change moves at the speed of trust.



- Stephen Covey
- Takes time
- Requires trusting relationships with partners
- Must truly value partner contributions

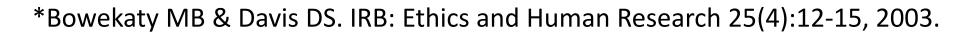
We Must Acknowledge History

"Theft has been the overriding experience of Native people in North America since the time of first contact..."*



Theft of: land, sovereignty, family members, language, culture, religion, knowledge, religious and cultural articles, Native symbols, ancestral bones, and more ...

Photo: Juliana M. Blome





2020-2021: Changes in the Social Landscape

"It is a priority of my Administration to make respect for Tribal sovereignty and self-governance, commitment to fulfilling Federal trust and treaty responsibilities to Tribal Nations, and regular, meaningful, and robust consultation with Tribal Nations cornerstones of Federal Indian policy."

Health Equity

- President Biden, Presidential Memo, January 26, 2021





Health Disparities

115TH CONGRESS 1ST SESSION

Inclusion

H. R. 40

To address the fundamental injustice, cruelty, brutality, and inhumanity of slavery in the United States and the 13 American colonies between 1619 and 1865 and to establish a commission to study and consider a national apology and proposal for reparations for the institution of slavery, its subsequent de jure and de facto racial and economic discrimination against African-Americans, and the impact of these forces on living African-Americans, to make recommendations to the Congress on appropriate remedies, and for other purposes.



Social Justice



Lakota Elder Helen 'Granny " Redfeather - By Ernesto Yereno Montejano



Building research partnerships for healthy Tribal Nations

Shifting Legal Landscape – Landmark U.S. Supreme Court Decision

McGirt v. Oklahoma – Decided July 9, 2020

- ➤ Case concerned whether Oklahoma could try a citizen of a Tribal Nation for criminal matters.
- McGirt contended that because his offenses occurred on lands guaranteed to the Muscogee Creek Nation in an 1866 treaty—one never legally extinguished by Congress—only Federal authorities could prosecute his case.

In a 5-4 decision, the Court ruled that Oklahoma remains Native Land.



Tribal rights, sovereignty, and jurisdiction are coming to the forefront in a historic way.



Former reservations of Cherokee, Chickasaw, Choctaw, Creek (Muscogee), and Seminole.



Respect for Tribal Sovereignty is Foundational



- ➤ Since the formation of the Union, the U.S. has recognized American Indian Tribes as **sovereign nations**.
- > Resulted in the transfer of land under treaties
- Federal programs and services that benefit American Indians and Alaska Natives (AI/AN) are based on this unique government-to-government relationship.
- > The relationship is political and legal. It is not based on race.
- The Federal government recognizes **574 Tribal Nations**, each with their own culture, language, government, and history.

The Treaty of Canandaigua, 1794. Parchment, ink, resin and wafer seals, ribbon. National Archives, Washington, D.C.



Reinforced Commitment to Tribal Sovereignty



BRIFFING ROOM

Memorandum on Tribal Consultation and Strengthening Nation-to-Nation Relationships

JANUARY 26, 2021 • PRESIDENTIAL ACTIONS

January 26, 2021

MEMORANDUM FOR THE HEADS OF EXECUTIVE DEPARTMENTS AND AGENCIES

SUBJECT: Tribal Consultation and Strengthening Nation-to-Nation Relationships

Executive Memorandum: January 2021

- Respect for Tribal Sovereignty
- Regular, meaningful, and robust consultation with Tribal Nations

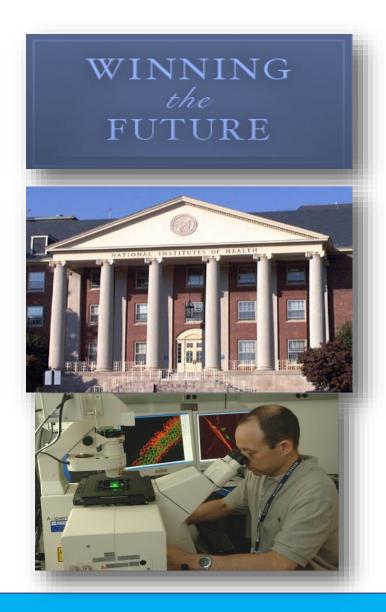
Presidential Memorandum: November 2009

 Requires agencies to prepare and update plans of action to implement EO 13175.

> Executive Order 13175: November 2000

 Charges all executive departments and agencies with engaging in regular, meaningful, and robust consultation with Tribal officials in the development of Federal policies that have Tribal implications.

NIH: Steward of Biomedical and Behavioral Research for the Nation

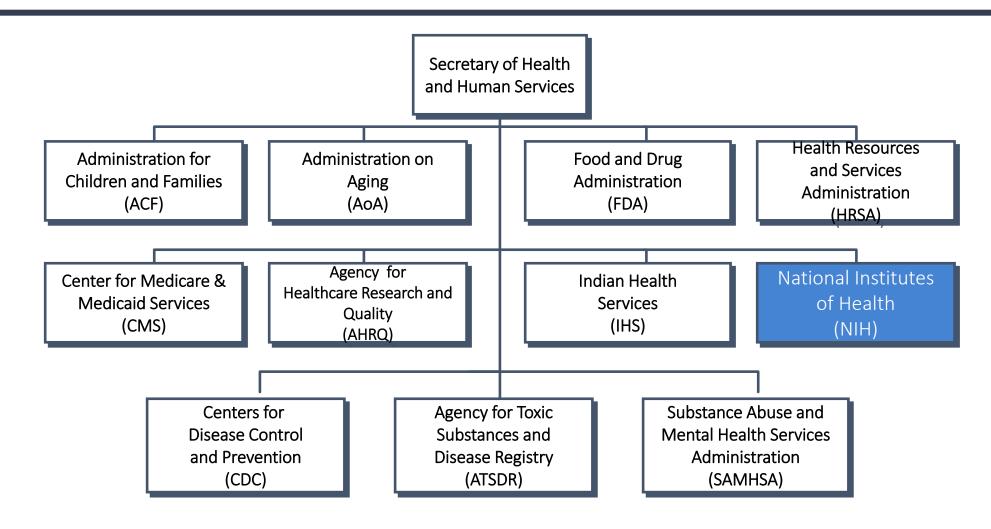


NIH's mission is to seek fundamental knowledge about the nature and behavior of living systems...

...and the application of that knowledge to enhance health, lengthen life, and reduce illness and disability.



The U.S. Department of Health & Human Services



Functions of the NIH Tribal Health Research Office (Established 2015)

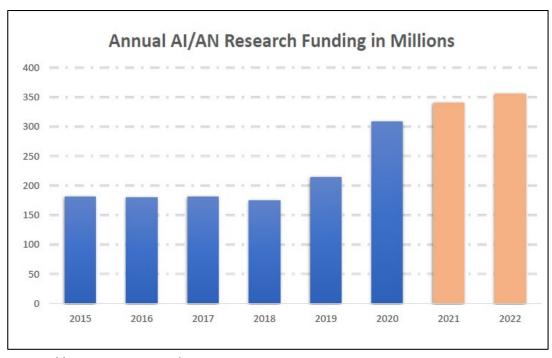


- ➤ Central hub for coordinating Tribal health research and AI/AN capacity building across NIH
- > Supports ICO efforts to meet Strategic Plan Goals
- > Ensures adherence to the NIH Tribal Consultation Policy
- > Gathers meaningful input from Tribal communities
- Convenes NIH Tribal Advisory Committee

NIH's AI/AN Research Portfolio – An Upward Trend

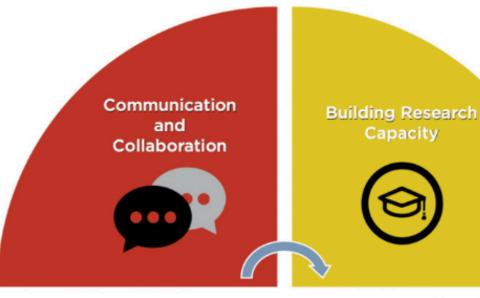
FY2018 Portfolio Analysis:

- ➤ NIH Investment of \$180M
- Supported 254 research base projects specifically focused on AI/AN health or community resource needs in FY18
- ➤ 10 ICs and the OD provided approximately \$141M or 78% of the funding
- > Funding level has remained relatively constant since FY15.
- > 43% Research
 - 30% Infrastructure and community outreach
 - 28% Workforce development
- ➤ 16% of the NIH AI/AN funding fell under umbrella funding opportunities, like **NARCH** and **IRINAH**.



https://report.nih.gov/





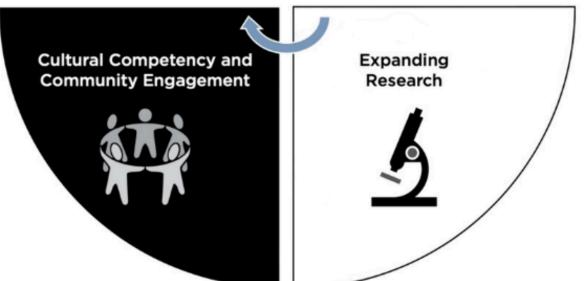


FY 2019-2023

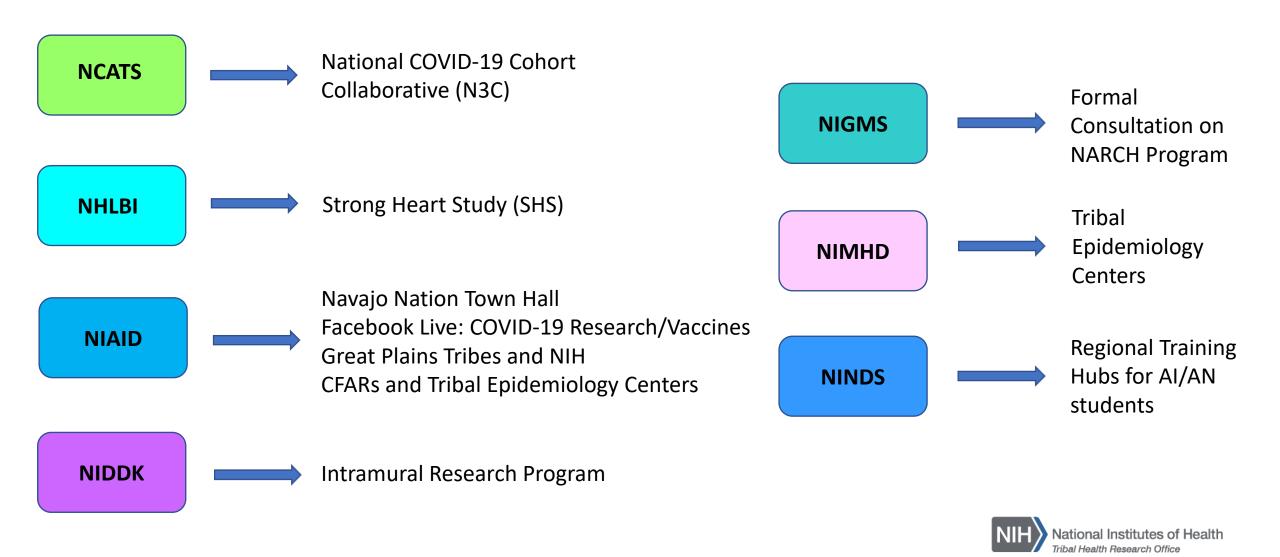
Goals aim to improve NIH relationships and collaborative efforts with American Indian and Alaska Native communities.

LEARN MORE!



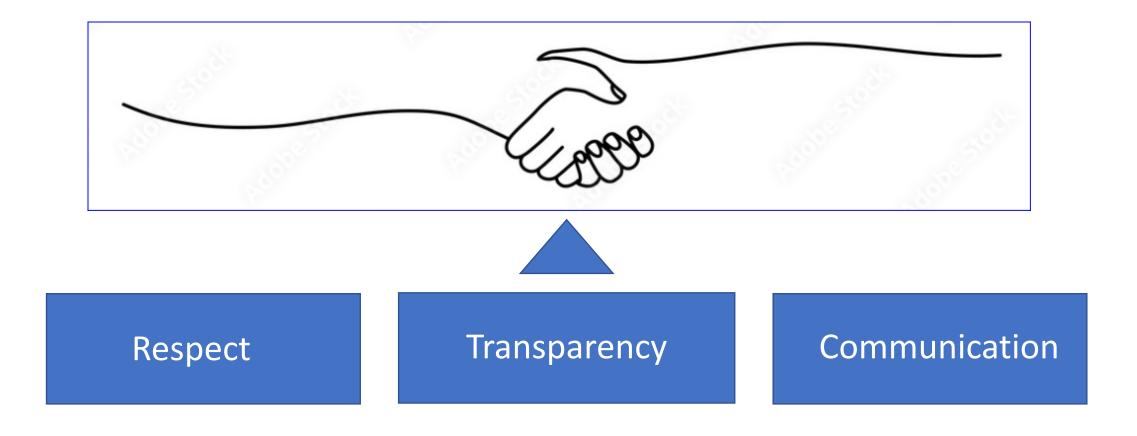


Working Across NIH – Partnering on Programs and Problem Solving



Building research partnerships for healthy Tribal Nations

Guiding Principles Support Efforts and Strategic Plan Implementation





New NIH Tribal Consultation Policy: Gathering Meaningful Input from Tribal Nations



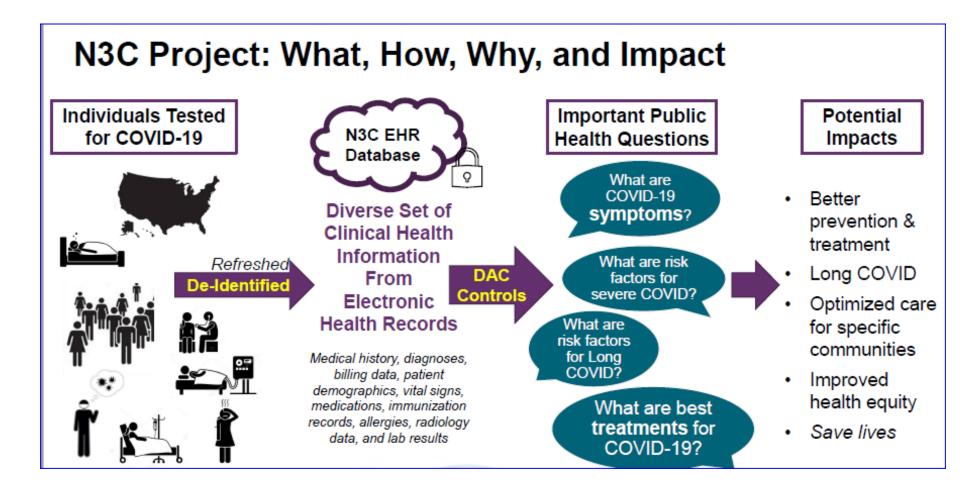
The National Institutes of Health (NIH) has a new Tribal Consultation Policy! Issuing this policy today is an important step that reflects NIH's commitment to sovereign Tribal Nations, a transparent and consistent Tribal Consultation process, and supporting the health of American Indians and Alaska Natives through biomedical and behavioral health research. With an emphasis on trust and shared responsibility, Tribal Consultation is a formal process for open and free exchange o... See more



• Policy includes:

- Definitions
- Objectives section
- Description of roles
- Details on process
- Reporting requirements
- Evaluation of meetings and process
- Regular assessment

Tribal Consultation on the National COVID Cohort Collaborative (N3C)



Tribal Consultation on Helping to End Addiction Long-Term Initiative

HEAL = A trans-agency effort to speed scientific solutions to stem the national opioid public health crisis in all communities

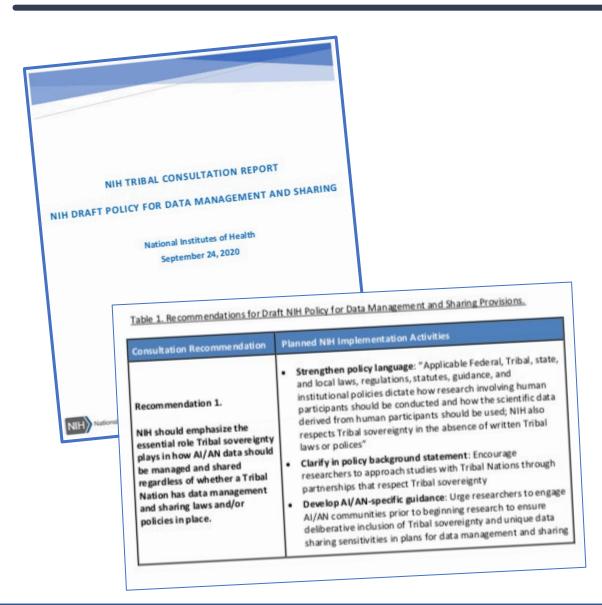
March 31, 2022

- What research priorities are important to AI/AN communities?
- How should HEAL engage with AI/AN communities to develop a Tribally focused initiative to speed development of scientific and local solutions to the opioid crisis?





Data Sharing and Management – Emphasizing Tribal Sovereignty



 "...recognizing that there may be unique concerns for AI/AN communities regarding broad data sharing, including circumstances in which broad data sharing may not be appropriate"

Consultation themes:

- Strengthen engagement built on trust
- Train researchers
- Align research practices with Tribal laws, policies, and preferences

Ethical Inclusion of Urban Indian Populations in Biomedical Research

- >7 out of 10 AI/ANs live in urban areas
- TAC Subcommittee

"to develop a framework and guidance for the ethical conduct of NIH research with Urban AI/AN populations that falls geographically outside the jurisdiction of Federally recognized Tribes under sovereignty-based research regulations"

AJPH PERSPECTIVES

Responsible Research With Urban American Indians and Alaska Natives

Rosalina D. James, PhD, Kathleen M. West, PhD, Katrina G. Claw, PhD, Abigail EchoHawk, MA, Leah Dodge, MPH, Adrian Dominguez, MPH, Maile Taualii, PhD, Ralph Forquera, MPH, Kenneth Thummel, PhD, and Wylie Burke, MD, PhD



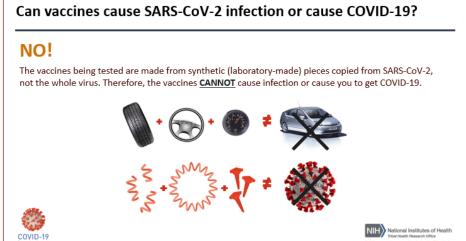
Promoting Ethical Research With American Indian and Alaska Native People Living in Urban Areas

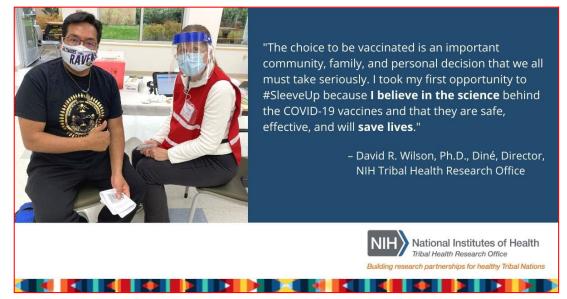
Nicole P. Yuan, PhD, MPH, Jami Bartgis, PhD, and Deirdre Demers, MPH

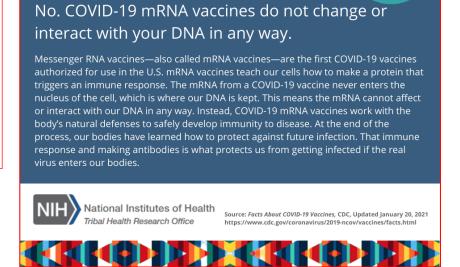


Communications – Clear, Culturally Appropriate, Responsive







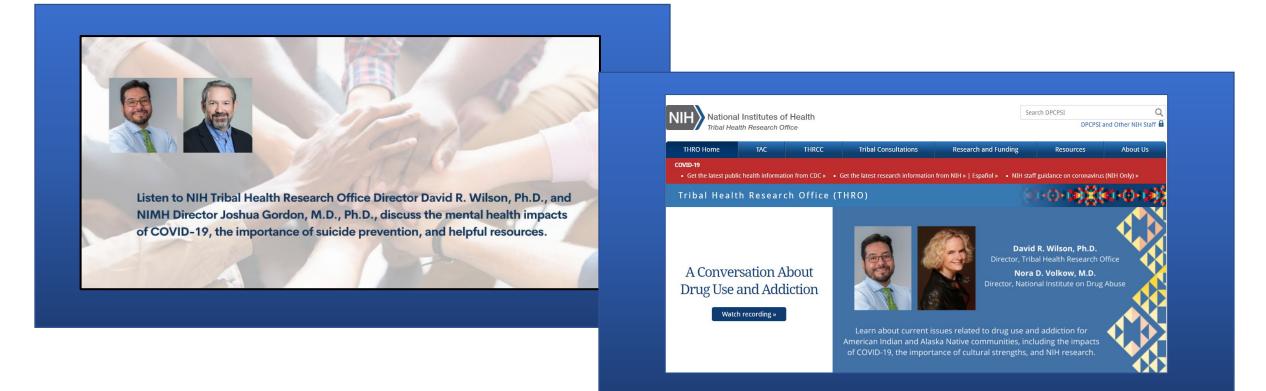


Will a COVID-19 vaccine alter my DNA?



Building research partnerships for healthy Tribal Nations

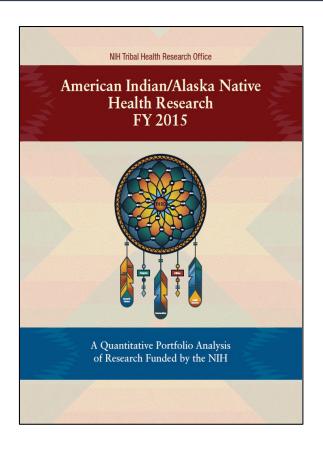
Addressing Health in AI/AN Communities

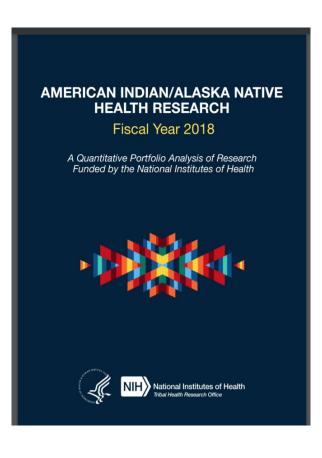


- Responding to interests of Tribal communities
- Increased interest from other ICs about outreach to Tribes
- THRO supporting ICs to do more
- Enhancing agency interest in cultural competency



Building Research Capacity for AI/AN Communities





- Forming collaborative partnerships
- Expanding support for AI/AN researchers
- Working to increase the number of AI/AN students pursuing research careers
- Engaging ICOs to expand NIH research with AI/AN communities

Summer Internships at NIH

TRAINING & CAREER DEVELOPMENT

High School, Undergraduate, & Post-Baccalaureate

Predoctoral Fellows

Postdoctoral Fellows

Clinician-Scientists

Faculty

Diversity Awards

Individual Fellowships

Career Development Awards

Institutional Grants

Other Training-Related Programs

NINDS Health Disparities in Tribal Communities Summer Internship Program (SIP)

COVID-19 UPDATE: We are now able to share information regarding the 2021 NINDS/NIH Summer Internship Program (SIP), High School Summer Internship Program (HS-SIP) and the Health Disparities in Tribal Communities Summer Internship Program.

Unfortunately, it is clear that we still face uncertain times with continuing difficulty integrating trainees who started during the pandemic. Therefore, we want to let you know that all 2021 NINDS Summer programs will be fully virtual this summer. The 2021 Summer Program Cohorts has been selected. We look forward to the next application cycle starting in mid-November 2021.

For information about COVID-19 , visit the following link: https://www.nih.gov/health-information/coronavirus

LATEST UPDATES



NINDS Strategic Plan 2021-2026

Graduate and undergraduate students selected for this fully-funded summer internship

Contact

Angel de la Cruz Landrau, PhD 301-496-0899 ninds-sip@ninds.nih.gov⊠







Expanding Research



NIH Common Fund Programs





THRO Engagement During Vaccine Development: A Holistic Approach

Operation Warp Speed (Interagency Partnership)

US Dept. of Health & Human Services, including:

- Centers for Disease Control and Prevention (CDC)
- Food and Drug Administration (FDA)
- National Institutes of Health (NIH)
- Biomedical Advanced Research and Development Authority (BARDA)

Other Federal Agencies:

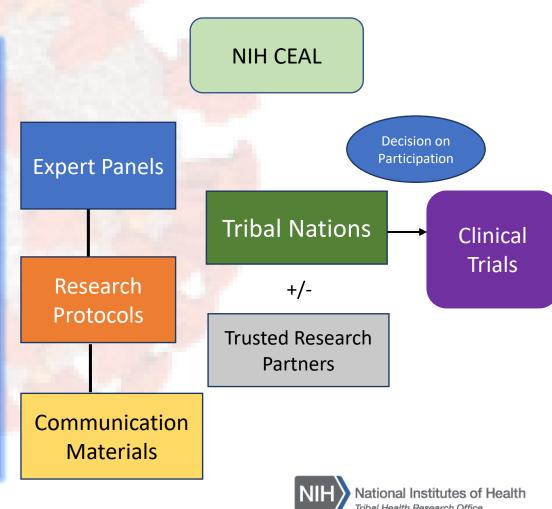
- Dept of Defense (DOD)
- Dept of Agriculture (USDA)
- Dept of Energy (DOE)
- Dept of Veterans Affairs (VA)

Private firms

NIH COVID-19 Prevention Network (CoVPN) Supports Operation Warp Speed

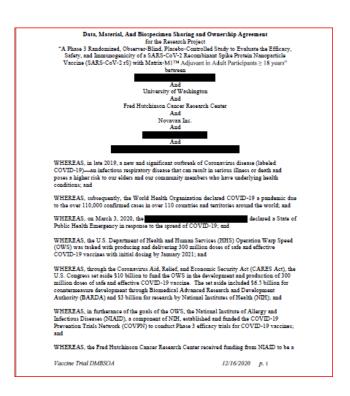
Created by merging four existing **NIAID-funded clinical trials** networks:

- •HIV Vaccine Trials Network (HVTN), Seattle, WA
- HIV Prevention Trials Network (HPTN), Durham, NC
- Infectious Diseases Clinical Research Consortium (IDCRC), Atlanta, GA
- AIDS Clinical Trials Group, Los Angeles, CA



Tribal Consideration to Participate in a Clinical Trial = Success

Groundbreaking agreement between Tribes and pharmaceutical companies



Tribal lawyers prepared template for model DMBSOA

Data, Material, And Biospecimen Sharing and Ownership Agreement

for the Research Project Between [name of parties]

WHEREAS, [background of need for agreement]

WHEREAS.

WHEREAS.

NOW THEREFORE, This Data, Material, and Biospecimen Sharing and Ownership Agreement ("Agreement") is entered between the (Tribe) and (other parties as necessary) individually a Party and collectively the Parties.

The parties are collaborating in the development, implementation, and dissemination of Tribe's participation in the Clinical Trial titled "[title of clinical trial] ("Research Project"). [name] is the Principal Investigator ("PI") at the. The [name of federal agency] funds this Research Project as described above.

I. PARTIES

[This section is intended to define the Parties]

In consideration of [describe consideration], [name parties] agree as follows:

II. PURPOSE OF RESEARCH PROJECT.

The purpose of the Research Project is to include [Tribe] as a participating organization in the conduct of the clinical trial entitled "title of research project."

III. PURPOSE OF AGREEMENT.

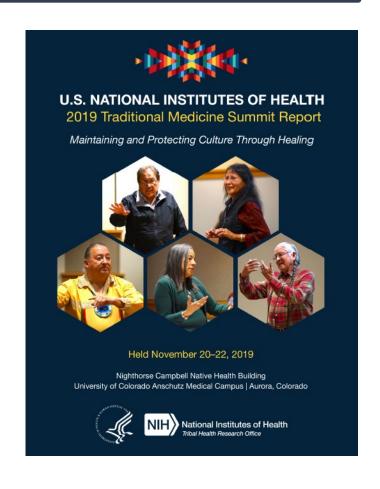
The history of research of American Indian/Alaska Natives included practices that directly violated Tribal Sovereignty and harmed both Tribes and Tribal people. Those violations nyolyed mis-analyzing research results to publish inaccurate and stigmatizing descriptions of the



Enhancing Cultural Competency and Community Engagement







- Increase awareness of Traditional ways of healing
- Begin the conversation on how research can benefit from cultural adaption
- Educate scientific community



Social Media: LinkedIn and Facebook

NATIVE AMERICAN RESEARCH CENTERS FOR HEALTH (NARCH) PROGRAM

The NARCH program supports research, research capacity building, and career enrichment to meet the health needs prioritized by American Indian and Alaska Native tribes or tribally based organizations.

LEARN MORE!









NIH SUMMER INTERNSHIP PROGRAM IN BIOMEDICAL RESEARCH (SIP)

THE APPLICATION FOR SUMMER 2022 IS STILL OPEN!

Apply by March 1 to this unique summer training opportunity for college, graduate school, and professional school students.







Radio Media Tour with Dr. Fauci – March 2021

Dr. Anthony Fauci participated in a radio media tour to address COVID-19 and vaccine hesitancy in AI/AN communities.

Initial Highlights:

- ➤ Nearly 4.5 million total impressions
- > 371 radio broadcasts with 2 million+ total audience
- > Additional soundbite distribution with 2 million+ audience

Listen! KNNB APACHE RADIO













Building research partnerships for healthy Tribal Nations

NATIVE AMERICAN HERITAGE MONTH

NIH TRIBAL HEALTH RESEARCH OFFICE







Building research partnerships for healthy Tribal Nations

Connect With Us and Learn More!



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Tribal Health Research Office,
DPCPSI, Office of the Director, NIH



A Mother's Love. Mallery Quetawki (Zuni Pueblo). University of New Mexico College of Pharmacy-Community Environmental Health Program.

Website

https://www.nih.gov/tribalhealth

Facebook

@NIHTribalHealth

LinkedIn

https://www.linkedin.com/showcase/ nih-tribal-health-research-office

