



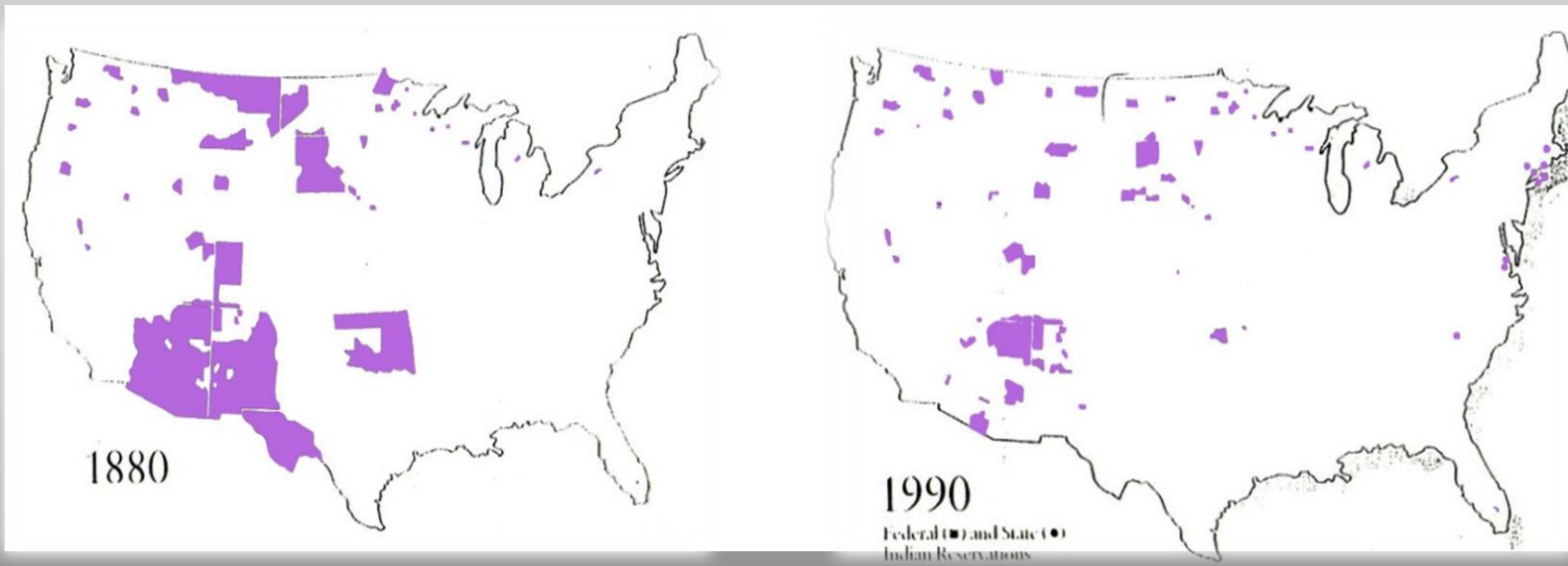
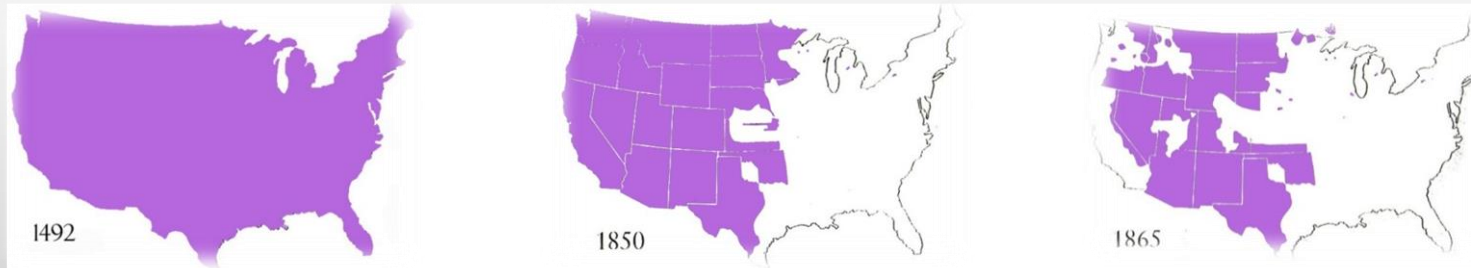
NIH Tribal Health Research Office Introduction and Update

USET Meeting
Choctaw, MS
November 5, 2019

David R. Wilson, Ph.D.
Director of the Tribal Health Research Office

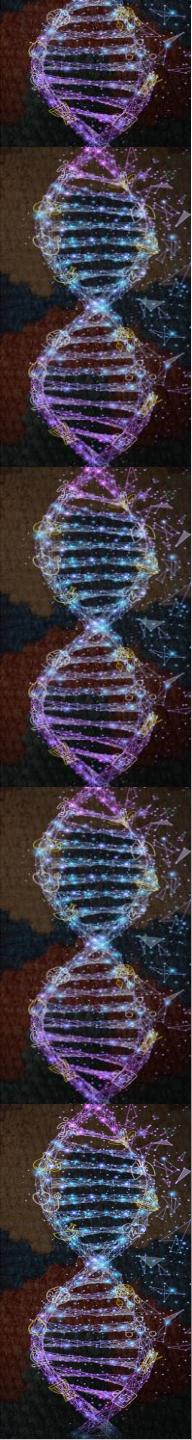


American Indian Reservations



Federal Trust Responsibility

- Since the formation of the Union, the United States (U.S.) has recognized Indian Tribes as sovereign nations.
- Resulted in the transfer of land under treaties
- Federal programs and services that benefit American Indians and Alaska Natives based upon concept of government-to-government relationship
- American Indians are provided healthcare as outlined in treaties

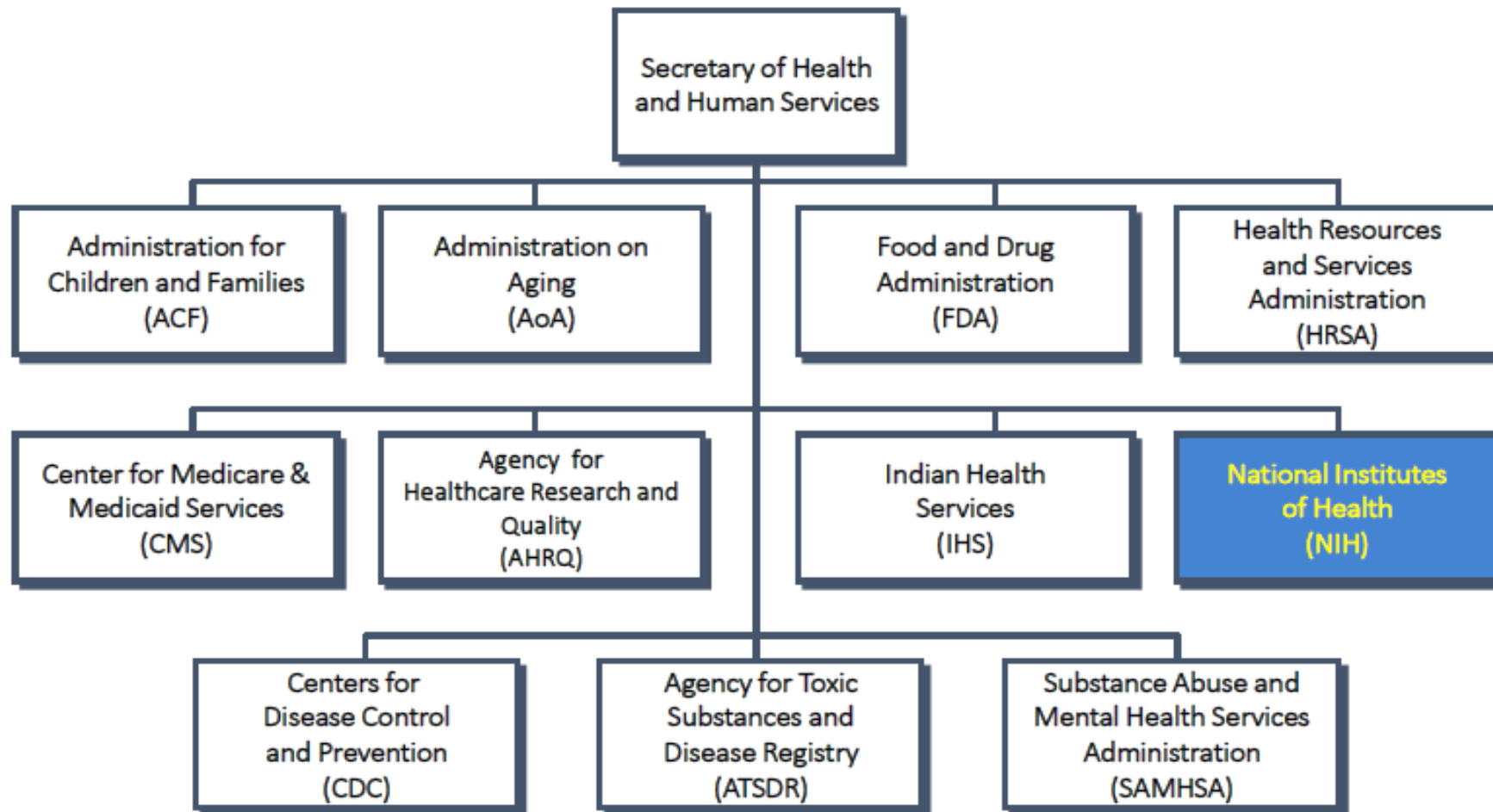


573* federally recognized tribes in the US with total citizenship of about 4.5 million people.

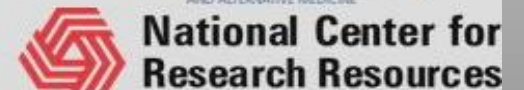
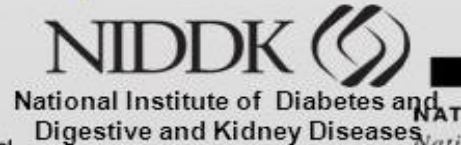
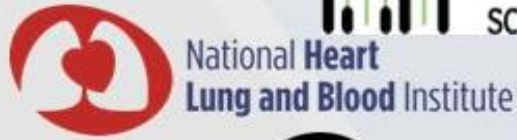
Each Tribe is unique and has different:

- Histories
- Cultural traditions
- Languages
- Government structures
- Institutions and systems
- Only ethnic minority in the US to have “Dual-Citizenship”

U.S. Department of Health & Human Services

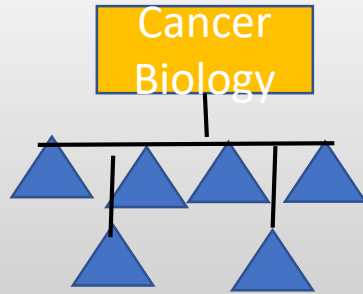


27 NIH Institutes and Centers

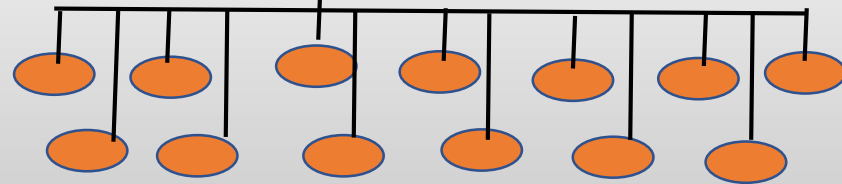


National Cancer Institute

Intramural divisions

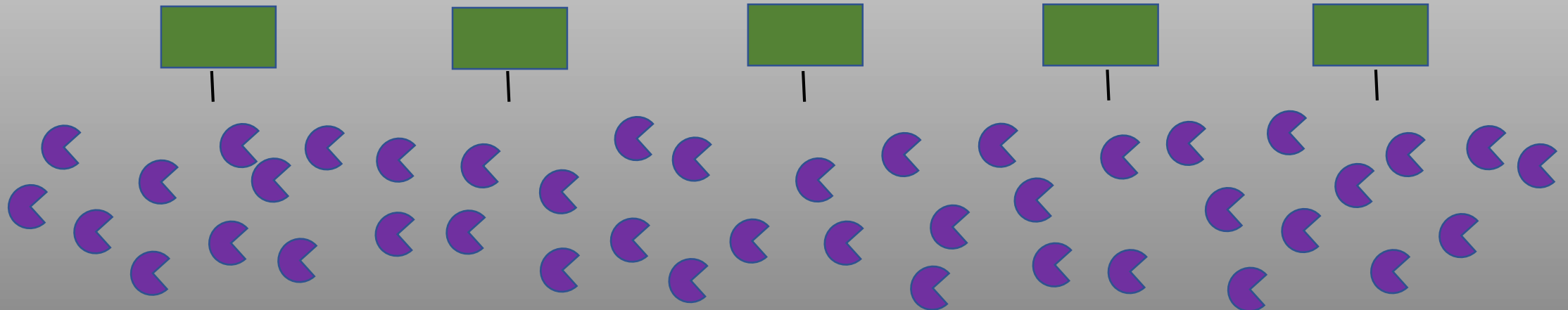


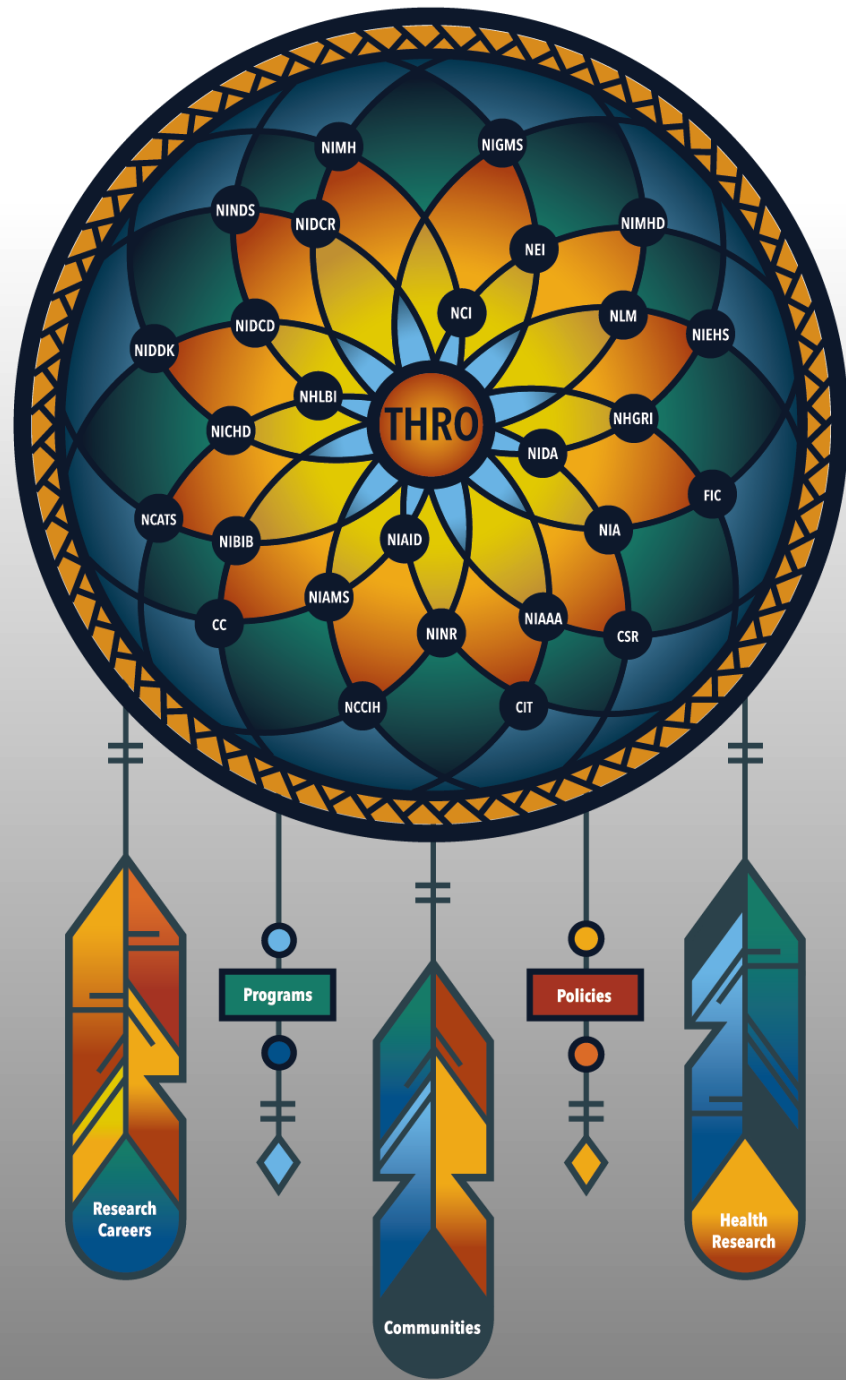
Population sciences



Research Programs

Extramural divisions





Established in 2015, the Tribal Health Research Office is located in ***the Division of Program Coordination, Planning, and Strategic Initiatives*** in the Office of the Director (OD), NIH.

The office was created in recognition of the importance of ensuring meaningful input from and collaboration with tribal Nations on NIH programs and policies.

To also ensure the effective implementation of the HHS Tribal Consultation Policy

NIH Tribal Advisory Committee



Tribal Health Research Coordinating Council THRCC

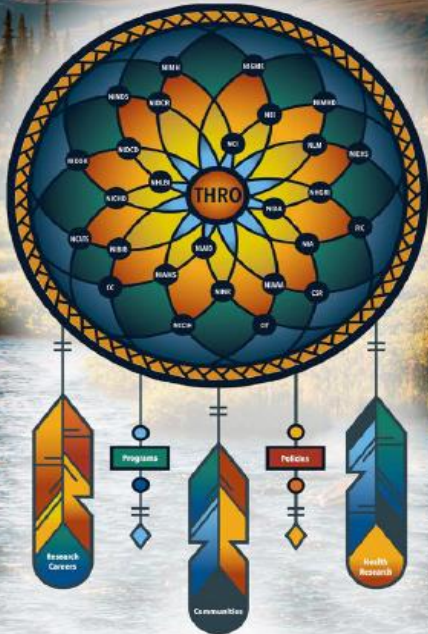


THRCC serves as a catalyst for developing research, research training, and career development initiatives focused on American Indians and Alaska Natives (AI/AN). It provides a forum for discussing the diverse health issues and challenges facing AI/AN communities, and how NIH research can help address those needs.



Notable Accomplishments

NIH Strategic Plan for
Tribal Health Research
FY 2019–2023



Strategic Goal 1:
**Enhancing Communication and
Collaboration**

Strategic Goal 2:
**Building Research Capacity for Tribes, Tribal
Organizations,
and Tribal Colleges and Universities**

Strategic Goal 3:
Expanding Research


Strategic Goal 4:
**Enhancing Cultural Competency and
Community Engagement**



First AI/AN Research Portfolio

NIH Tribal Health Research Office

American Indian/Alaska Native Health Research FY 2015



A Quantitative Portfolio Analysis of Research Funded by the NIH

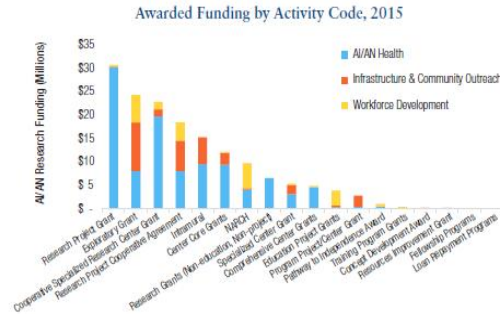


Figure 2. Awarded funding by activity code and research emphasis

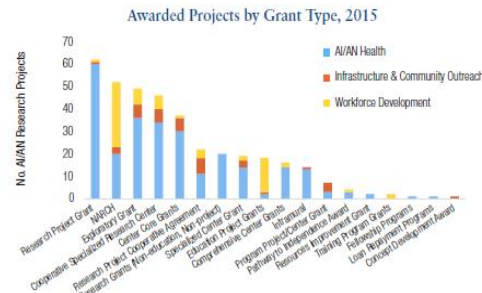


Figure 3. Awarded projects by activity code and research emphasis

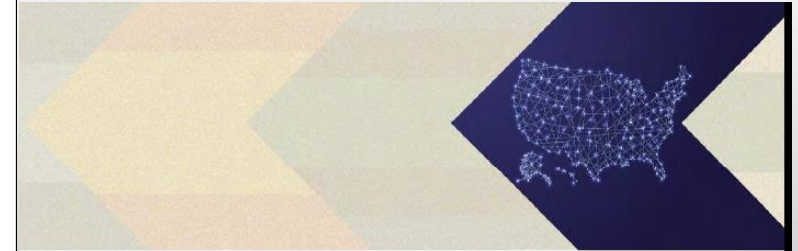


Table C. States with the highest percentage of funding or projects awarded, FY 2015



States with 80% of Total Funding, 2015	Funding, 2015 millions of \$ (%)	No. AI/AN Research Projects (%)	Major Research Sites*
Arizona	\$31.9 (20.2%)	66 (17.7%)	University of Arizona, Northern Arizona University, and NIH Intramural Phoenix Epidemiology and Clinical Research Branch
Washington	\$14.5 (9.2%)	45 (12.1%)	University of Washington and Washington State University
Oklahoma	\$14.1 (9.0%)	34 (9.1%)	University of Oklahoma Health Sciences Center
Alaska	\$11.9 (7.5%)	22 (5.9%)	University of Alaska Fairbanks
South Dakota	\$9.6 (6.1%)	18 (4.8%)	Sanford Research
New Mexico	\$8.4 (5.3%)	27 (7.2%)	University of New Mexico Health Sciences Center
Colorado	\$7.8 (5.0%)	23 (6.2%)	University of Colorado Denver
California	\$7.0 (4.4%)	16 (4.3%)	—
Montana	\$6.9 (4.4%)	16 (4.3%)	Montana State University – Bozeman
Kansas	\$6.2 (3.9%)	9 (2.4%)	—
Maryland	\$6.2 (3.9%)	13 (3.5%)	Johns Hopkins University
North Dakota	\$3.9 (2.5%)	4 (1.1%)	—
Totals†	\$128.5 (81.5%)	293 (78.6%)	


*Includes out-of-state collaborators and partner research sites.

†Due to rounding errors, totals may not add up precisely.

NIH/IHS/SAMHSA Tribal Consultation / Listening Session on the Opioid Crisis in Indian Country





 National Institutes of Health
Turning Discovery Into Health



**NIH/IHS/SAMHSA Tribal Consultation / Listening Session
 on the Opioid Crisis in Indian Country**

DATES: Monday, May 21 – Tuesday, May 22, 2018
LOCATION: Mystic Lake Center - 2400 Mystic Lake Boulevard, NW, Prior Lake, MN 55372
TIME: 8:45 am - 3:00 pm Central Time

HOSTED BY TIME: U.S. Department of Health & Human Services: National Institutes of Health, Indian Health Service, and Substance Abuse and Mental Health Services Administration

Purpose: To seek your input and discuss ways our agencies are working together to combat the opioid epidemic in Indian Country.

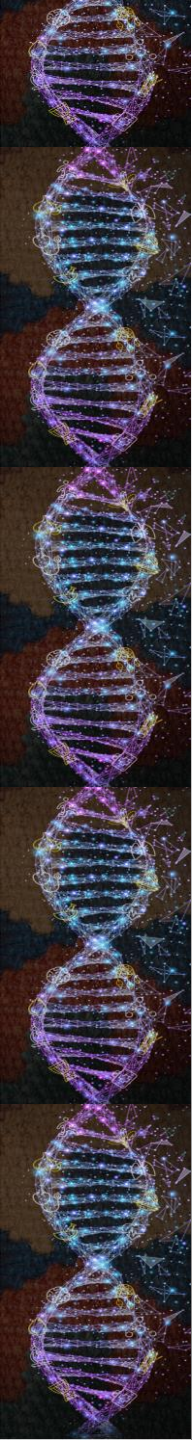
MODERATORS:

- Aaron Payment, MPA, Med, EdD, Tribal Advisory Committee Member (TAC), Tribal Chairman for the Sault Ste. Marie Tribe of Chippewa Indians
- Mirtha Beadle, MPA, Director, Office of Tribal Affairs and Policy (OTAP)

Toll Free Number: (866) 776-8102; Passcode: 81683639

Day 1 – May 21, 2018		
Schedule	Topic	Presenter/Facilitator
8:45 - 9:00 am	Opening Blessing	Aaron Payment, MPA, MEd, EdD Tribal Advisory Committee Member (TAC)
9:00 - 9:15 am	Welcome and Introductions <ul style="list-style-type: none"> Opening Remarks Introductions Consultation Procedures 	Mirtha Beadle, MPA, Director, Office of Tribal Affairs and Policy (OTAP)
9:15 - 10:15 am	Opioid Research and Health in American Indian/Alaska Native (AI/AN) Communities	David R. Wilson, Ph.D. Director, NIH Tribal Health Research Office
		Ngia Volkow, M.D. Director, National Institute of Drug Abuse (NIDA) National Institutes of Health

Page 1 of 4



Better Access to NIH Data



AI/AN Health Research Grant Finder

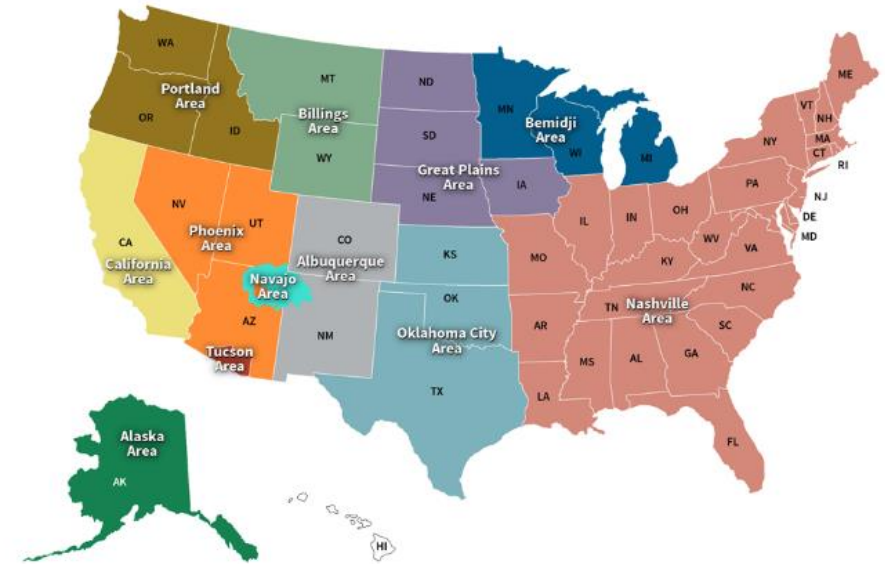
FY 2016 - Portland Area

Select a Report Year

- FY 2016
- FY 2015
- FY 2014

Select a Tribal Area

- Alaska Area
- Albuquerque Area
- Bemidji Area
- Billings Area
- California Area
- Great Plains Area
- Nashville Area
- Navajo Area
- Oklahoma City Area
- Phoenix Area
- Portland Area**
- Tucson Area

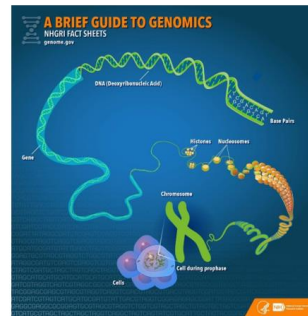
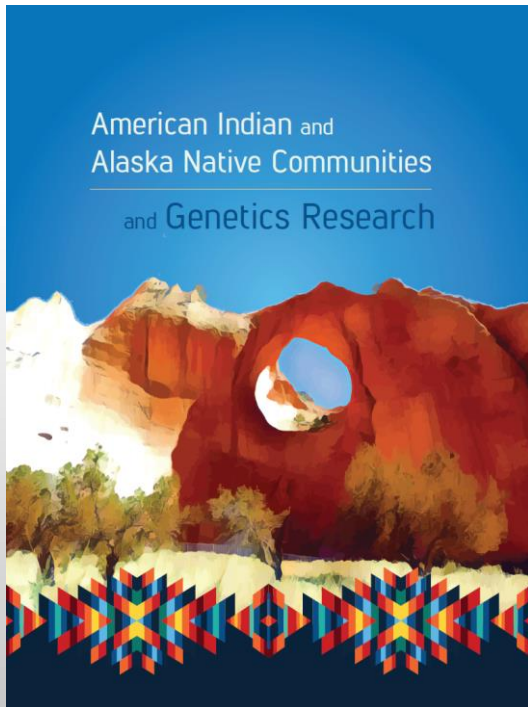
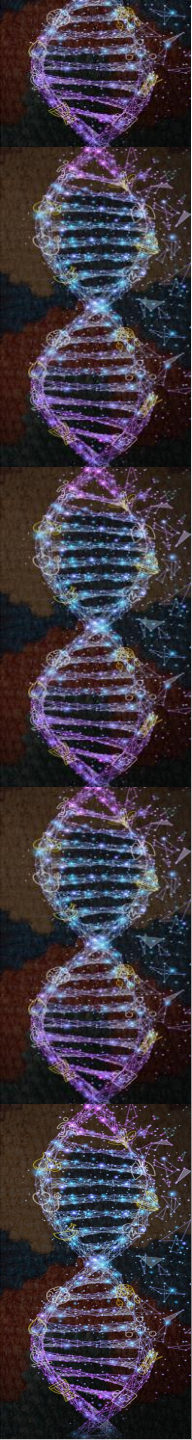


Please note, this page provides highlights found in the more exhaustive FY 2016 Report [pdf](#). To submit feedback, email NIHTribalCommittee@od.nih.gov

[View the full listing of AI/AN research projects for FY 2016 - Portland Area on NIH RePORTER »](#)

FY 2016 - Portland Area

Program	Organization	Admin IC
Caring Texts: A Strength-based, Suicide Prevention Trial in Four Native Communities	Washington State University	NIMH
Contingency Management Treatment of Alcohol Abuse in American Indian People	Washington State University	OD/NIAAA
Increasing AI/AN Research Engagement through a Culturally Adapted Ethics Training	University of Washington	NICHD
Indigenous HIV/AIDS Research Training Program	University of Washington	NIMH
Multigenerational Household Intervention to Reduce Stroke and Cardiovascular Disease	Washington State University	NHLBI
Preventing HIV among American Indians through the Treatment of PTSD and Substance Use	University of Washington	NIMHD
Tribal Colleges and Universities Behavior Wellness Study	University of Washington	NIAAA



1. Image from <https://www.genome.gov/18015865/a-brief-guide-to-genomics/>

What is the human genome and why is it important?

Genome is just a fancy word for all your DNA. Your genome contains all the instructions for you to grow through, instructor your biolo Half of you your moth father. Th instructor your heigh whether o

or at risk for some diseases, including some types of cancer.

Humans are very similar; we share 99.9% of DNA with each other. The differences, or genetic variants, are what result in the differences in our physical traits. They are what make you unique.

However, your genome is only one part of what determines your

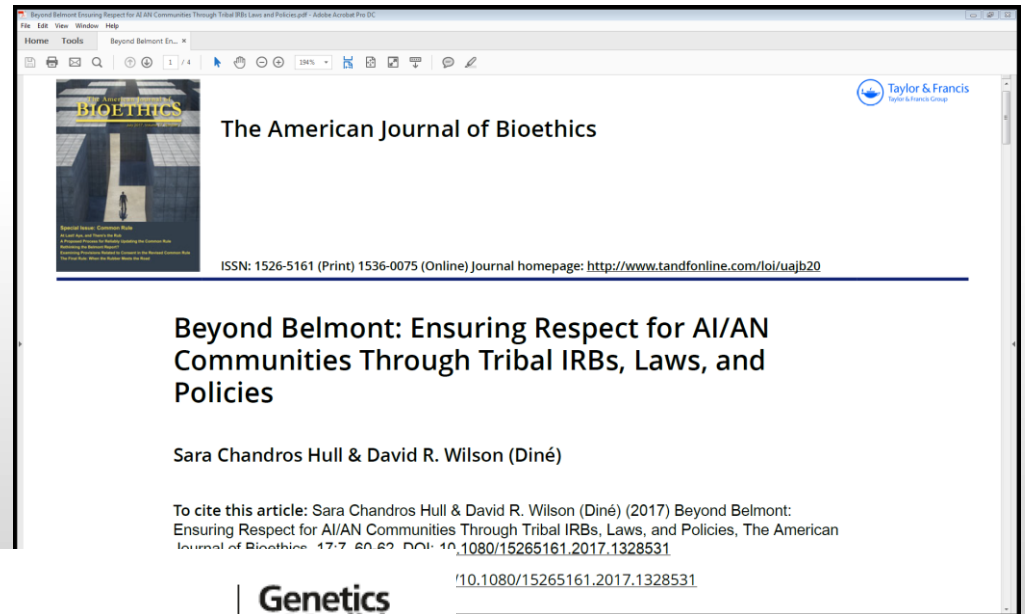
Interactions can affect your traits and disease risks. For example, if a person is at higher risk than average for becoming diabetic because she has three or four gene variants that elevate her risk, it does not mean that she will definitely become diabetic. Instead, what she eats, how much she exercises, and other factors influence her overall risk of becoming diabetic.

How do we learn about our individual genomes?

There are different ways to look at the genome, depending on what information you're seeking. Healthcare providers and researchers can perform genetic tests to learn a variety of things about your genome. In order to conduct these tests, DNA is collected from blood, saliva, or tissue. Currently, in clinical care, health care providers use genetic tests to diagnose or assess genetic risk for specific diseases.

The genome can be read in its

American College of Medical Genetics and Genomics



ARTICLE | Genetics in Medicine



Constructing identities: the implications of DTC ancestry testing for tribal communities

Hina Walajahi, BS¹, David R. Wilson, PhD² and Sara Chandros Hull, PhD^{1,3}

Purpose: Direct-to-consumer (DTC) genetic ancestry companies have rapidly increased in popularity, with top testing services maintaining genetic databases of several million consumers. While genetic ancestry tests are often characterized as recreational, companies invoke deeply personal concepts of individual identity, group membership, and kinship when marketing their services. In particular, many companies claim to be able to determine Native American heritage, claims that are not supported by the state of the science and may have significant cultural and political consequences for US tribal communities. This study aims to fill the gaps in empirical work on this issue and characterize how genetic ancestry companies articulate indigenous identity through their marketing strategies.

Methods: We conducted a qualitative content analysis of the public facing websites for 25 DTC genetic ancestry companies that offer services measuring Native American ancestry.

Results: Our findings describe how genetic ancestry companies promote a causal relationship between genetics and self-identity through marketing language such as "Discover Yourself" and "Are you Native American?" and how this may affect US tribal communities.

Conclusion: Genetic ancestry company claims regarding genetic ancestry, personal identity, and cultural membership are problematic and challenge how US tribal nations currently identify and create potential obstacles for tribal sovereignty.

Genetics in Medicine (2019) <https://doi.org/10.1038/s41436-018-0429-2>

Keywords: indigenous identity; direct-to-consumer; commercial ancestry test; Native American; empirical bioethics

[10.1080/15265161.2017.1328531](https://doi.org/10.1080/15265161.2017.1328531)

NIH Workshop on Genetic Research



NEWS IN FOCUS

ENVIRONMENT Brazilian science agencies face a worsening budget crisis **p.102** | **ECOLOGY** Project charts long-term changes in California desert ecosystems **p.103** | **GENETICS** Gene study uses tissues from recently deceased individuals **p.104** | **WASTE** Weapons-lab refuse will be trapped in glass **p.112**

The Navajo Nation's vast reservation in the southwestern United States is home to 174,000 people.

Navajo Nation reconsiders ban on genetic research

Tribal leaders are developing a policy for DNA analysis and data sharing.

BY SARA REARDON

When the Navajo Nation opens its first oncology centre next year in Tuba City, Arizona, clinicians there may be able to offer a service that has been banned on tribal lands for 15 years: analysing the DNA of Navajo tribe members to guide treatment and study the roots of disease.

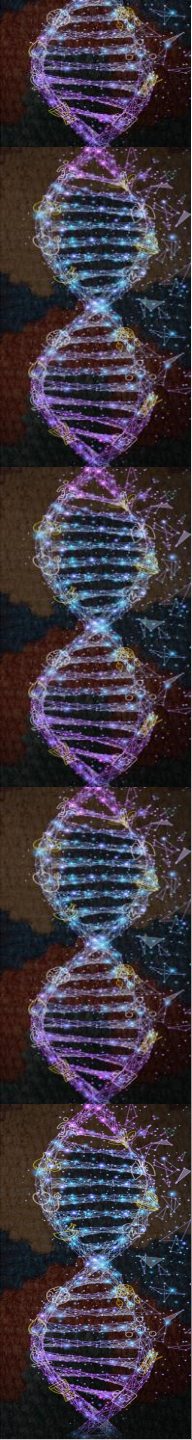
That's because the Navajo, the second-largest Native American group in the United States, are considering whether to lift their long-standing moratorium on genetic research. The tribal government banned DNA studies in 2002 to prevent the misuse of its members' genetic material. Although there is still some apprehension about allowing researchers access to Navajo DNA, the tribe's leaders increasingly see genetic research as a tool to improve medical care for the 174,000 residents of their sprawling reservation, which is roughly the size of Scotland.

As it now stands, Navajo people who live on the reservation must drive hundreds of kilometres to access specialized medical care off tribal lands, in large cities such as Phoenix, Arizona. "We spend millions of dollars outsourcing [care] for cancer and diabetes," says Walter Phelps, a delegate to the Navajo Nation Council. As the tribe — a nation independent of the United States — tries to expand the health services it offers, he says, "the moratorium could become a barrier when blood and tissue have to be collected".

Phelps is now working on the effort to create a policy by which the Navajo Nation would approve genetic-research projects

12 OCTOBER 2017 | VOL 356 | NATURE | 143

© 2017 Macmillan Publishers Limited, part of Springer Nature. All rights reserved.



Navajo Nation Signing Ceremony for the ECHO Data Sharing Agreement

At Navajo Nation
Head Start Center
in Leupp, AZ



NATURE NEWS

07 MAY 2019

Navajo Nation and US health agency reach data-sharing agreement

Researchers funded by the National Institutes of Health will have access to health information from tribe members.

Sara Reardon



A wide, calm river flows under a heavy, overcast sky. The water is a dark, greyish-brown color, reflecting the light from the clouds. The far bank is lined with a dense forest of trees, their colors muted by the overcast light. In the foreground, the sandy shore is cluttered with a large pile of driftwood, including branches, logs, and twigs. The overall mood is somber and atmospheric.

Current Efforts

NHLBI and THRO efforts for the Strong Heart Study

Havasupai Genetic Research Case Settled

After seven years of legal arguments, Arizona State University reached a settlement agreement with the Havasupai Indian tribe. The University paid \$700,000 to 41 tribe members, returned blood samples it had been collecting since 1990, and agreed to provide other services to the tribe such as scholarships and assistance in funding a new health clinic. Perhaps most important, however, is the heightened awareness this case has brought to issues surrounding informed consent, vulnerable populations, and medical and scientific research. (2011)



This example of research misconduct is most notable but not the only of its kind.

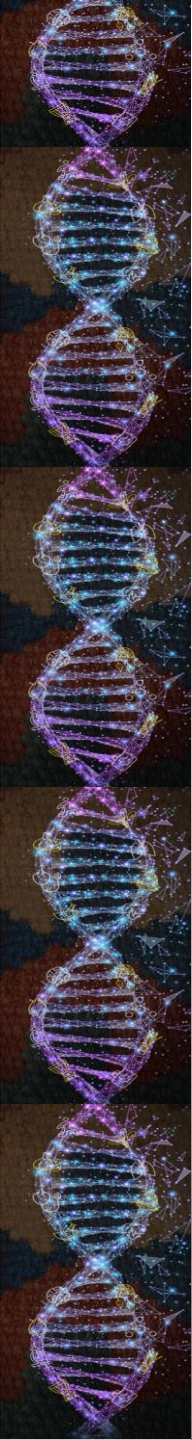
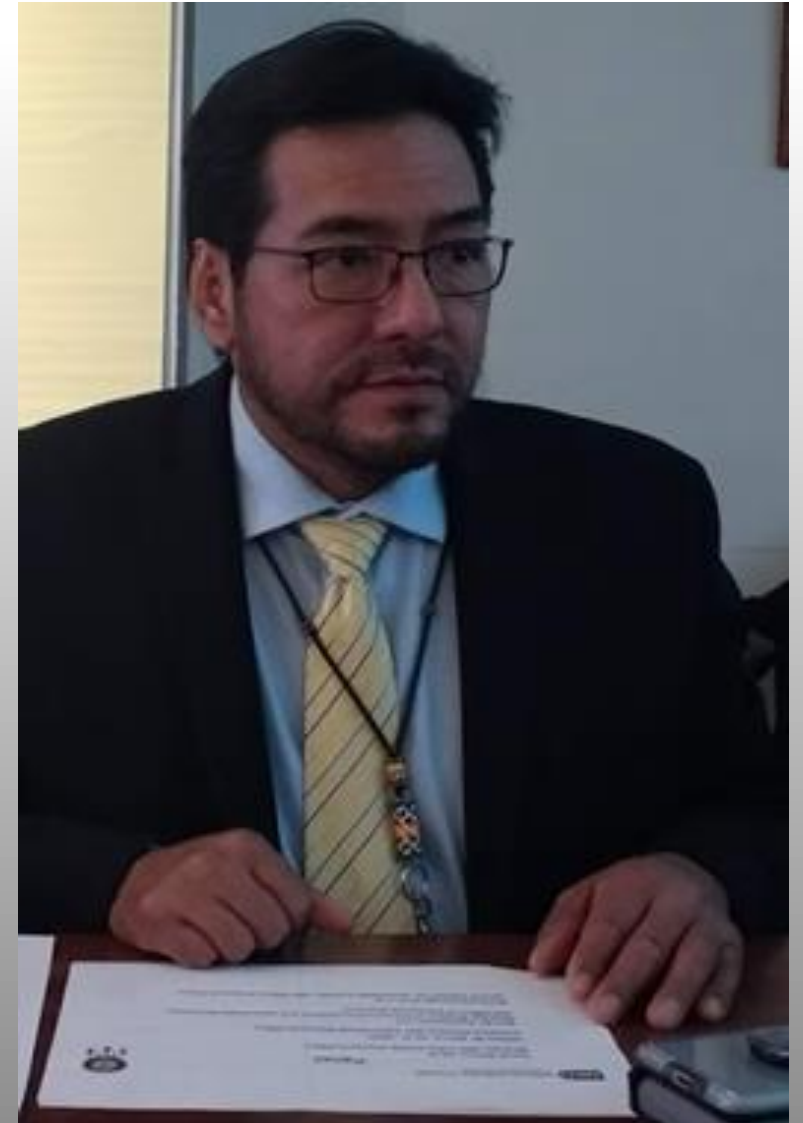
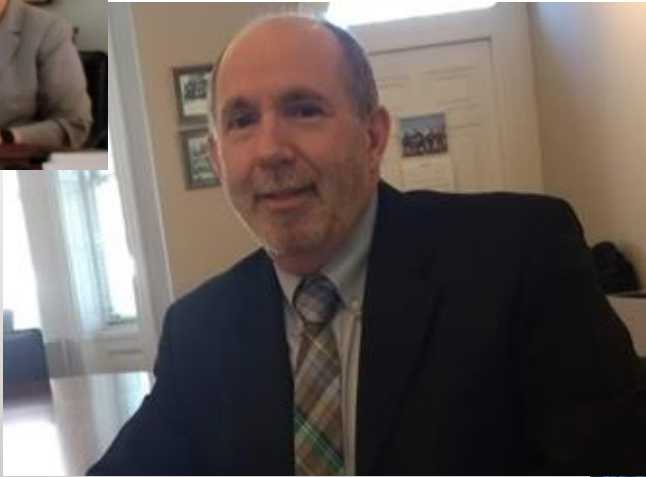
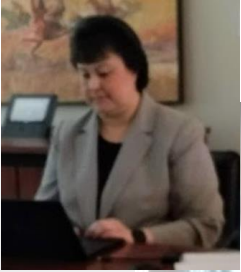


Tribal Epidemiology Centers Consortium Meeting Rapid City, South Dakota – October 2019



- NIH Tribal Health Research Office, Office of AIDS Research, NIAID

**Webinar on Intellectual Property
and
Data Sharing and Management**
*in collaboration with National
Congress of American Indians
(NCAI)*





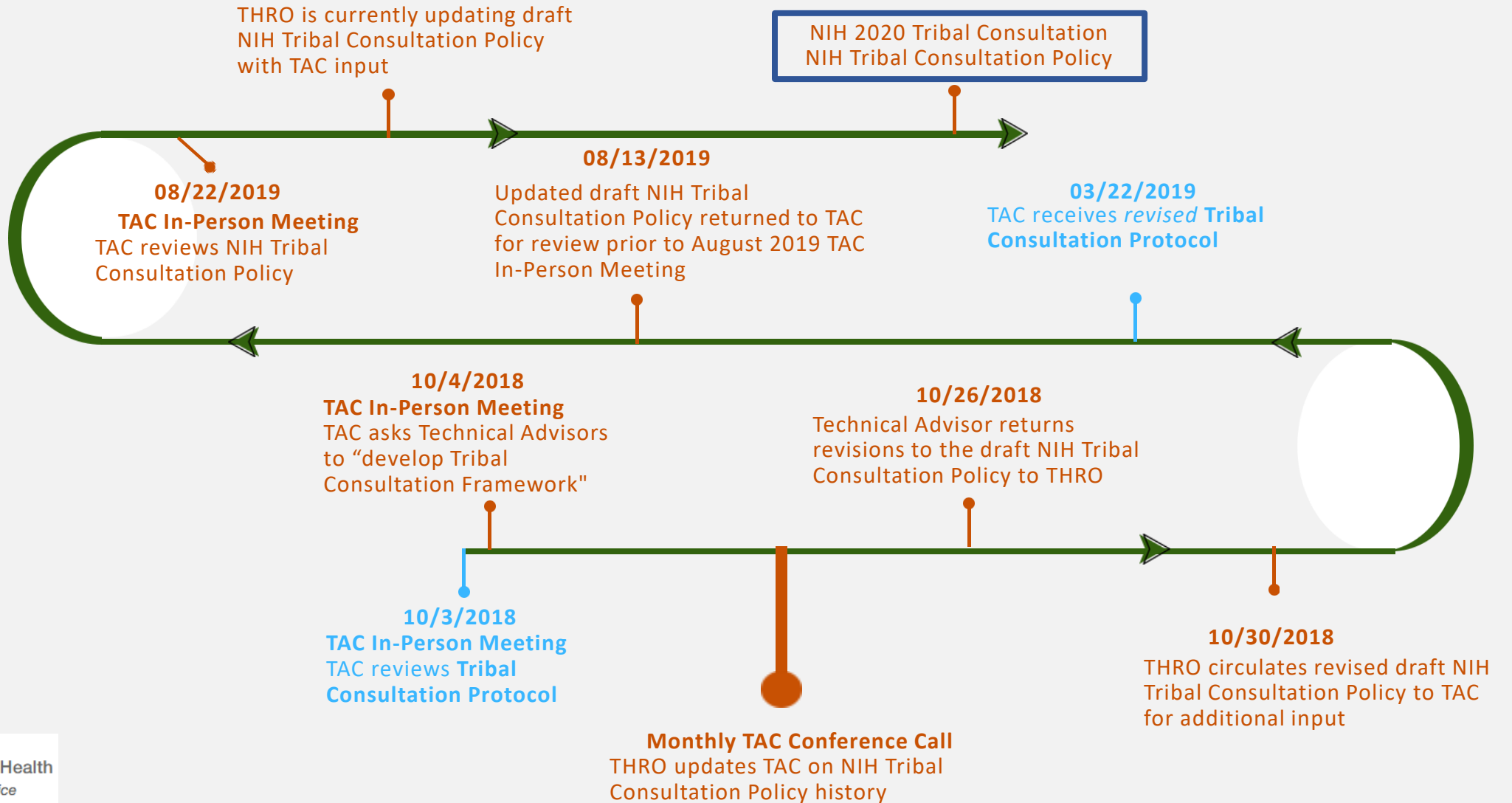
NIH Tribal Consultation Policy

The NIH TAC and THRO are developing a process for the agency to formally consult with Tribes

NIH Strategic Plan for Tribal Health



NIH Tribal Consultation Policy Development Timeline



Draft NIH Consultation Protocol

1) NIH Annual Consultation Timeline (approximate)



6-Months Prior: Identification of need / consultation focus

- TAC, AI/AN Tribe, or NIH proposal on focus of consultation
- Identify stakeholders (e.g. AI/AN organizations, academic institutions)
- Short description: Meaning of [Tribal consultation](#)

5-Months Prior: Consultation Logistics Planning

- Establish ad hoc Tribal consultation planning committee
- Identify location
 - * Consider existing events to align with and other strategies to maximize attendance
- Identify speakers
- Identify funding ICOs / support mechanisms
- Draft agenda (minimize presentation time; maximize discussion)
 - *Discuss potential outcomes with community stakeholders
- Establish strategy for material dissemination (hard copy, web, etc.) including post-consultation

4-Months Prior: Information Dissemination/Sending Invitation: (e-mail, webinar, flyers, etc.)

- *Discuss invitees with Tribal consultation planning committee
- E.g. Tribal leadership & community stakeholders, NIH leadership, AI/AN researchers & academic partners, HHS and Agency partner representatives, other stakeholders

3-Months Prior: Registration/Attendance Tracking

Logistics Monitoring

- Confirm venue and necessary technology
- Agenda final details in place

- Materials to be printed/disseminated prepared
- Request speaker presentations

*Consider requesting feedback from Tribal or community representatives

- Dear Tribal Leader Letter To Tribal Leaders / TAC 60 days prior ([example](#))

1-Month Prior

- Publish [Dear Tribal Leader Letter](#) 30 days from Consultation ([example](#))
- Publish [Framing Letter](#) 30 days from Consultation ([example](#))

Logistics Monitoring

- Establish Federal Registry Notice
- Receive Presentations ([example](#))
- Hold pre-meeting briefing with federal staff and tribal moderators
- Perform dry-run with web presentation platform
- Distribute agenda to all contacts

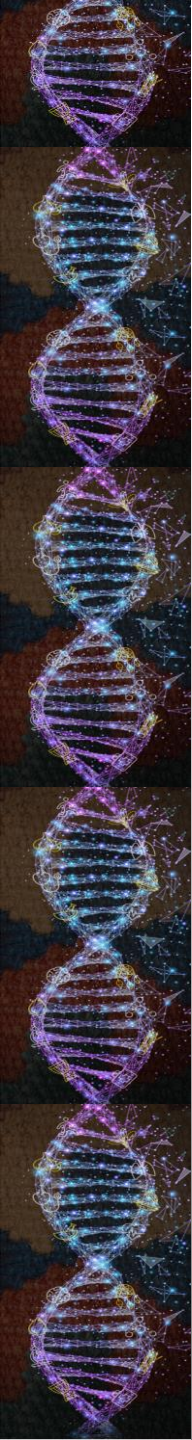
Post-consultation activities

October, 2019 : NIH is awaiting input to the themes communicated during the NIH 2019 Tribal Consultations on Intellectual Property in Biomedical Research and NIH Data Sharing and Management Policy.

- Mechanism to solicit feedbacks e.g., RFI
- Archive consultation summary
 - Include positions and issues raised that would benefit from ongoing consultation
- Archive videocast (if applicable)
- IC POC track issues requiring follow-up, reported to the Indian Tribes as soon as feasible or within 90 calendar days of the consultation session.



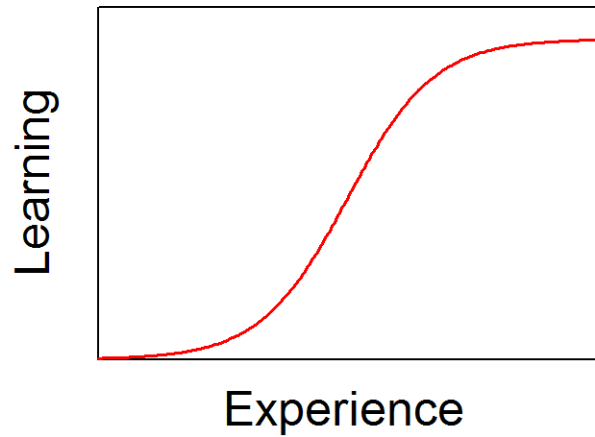
Summer Internship Students & Activities



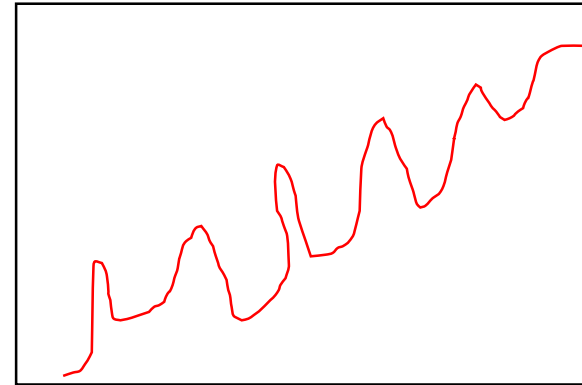
Visit to Pacific Northwest
University Roots to Wings
Program_July 8, 2019

The Learning Curve

S-Curve (Sigmoid)



Actual



© Alan Fletcher 2013 This file is licensed under the Creative Commons Attribution-Share Alike 3.0 Unported
Drawn with 'R' using R-studio

Scientific Community Engagement

- Substance use and mental health challenges have been identified as major public health concerns linked to decreased quality of life and life expectancy across America.
- These challenges disproportionately affect some Indigenous communities, yet existing data reveal high rates of abstinence and recovery among Indigenous people.
- Using data from NIH funded studies, this lecture will describe trajectories of early life course substance use, mental health challenges, and enduring mental health among Indigenous people in North America.



2019 NATIONAL NATIVE AMERICAN HERITAGE MONTH LECTURE

IMPROVING AMERICAN INDIAN AND
ALASKA NATIVE HEALTH THROUGH RESEARCH

GUEST SPEAKER Melissa Walls, Ph.D.

Bois Forte and Couchiching
First Nation Anishinaabe Bands

Director

Great Lakes Hub for the Johns Hopkins Center for
American Indian Health

Associate Professor

Johns Hopkins Bloomberg School of Public Health



HOSTED BY

NIH Tribal Health
Research Office (THRO)

The NIH THRO invites you to join us in celebrating 2019 National Native American Heritage Month (NNAHM). This year's special guest lecturer is Dr. Melissa Walls, Director of the Great Lakes Hub for the Johns Hopkins Center for American Indian Health and Associate Professor at the Johns Hopkins Bloomberg School of Public Health.

David R. Wilson, Ph.D.
Director
Tribal Health Research Office
Office of the Director

Individuals with disabilities who need reasonable accommodation to participate in this event should contact Karen Hughes: karen.hughes@nih.gov, 301-402-9852, and/or the Federal Relay (1-800-877-8339)

**Watch the NNAHM
lecture online**

Substance use and mental health challenges have been identified as major public health concerns linked to decreased quality of life and life expectancy across America. These challenges disproportionately affect some Indigenous communities, yet existing data reveal high rates of abstinence and recovery among Indigenous people. Using data from NIH funded studies, this lecture will describe trajectories of early life course substance use, mental health challenges, and enduring mental health among Indigenous people in North America. Through recognition of Tribal sovereignty and the use of Tribally-based participatory approaches, research can serve as a valuable tool that highlights the value of within-culture studies, informs preventive interventions, and creates new narratives about Indigenous healthy living and well-being.

Dr. Walls works in collaboration with American Indian and First Nations communities to identify key drivers of community health. She and her team translate research outcomes to influence the development of culturally relevant policies and programs that improve the health of Indigenous communities. Her involvement in community-based participatory research projects includes mental health epidemiology; culturally-relevant, family-based substance use prevention, and mental health promotion programming and evaluation; and examining the effects of stress and mental health on diabetes.

Dr. Walls is a principal investigator for NIH Research Project Grants, a member of the National Advisory Council on Drug Abuse, and a mentor to American Indian students. She received her Ph.D. from the University of Nebraska-Lincoln after serving as a National Institute of Mental Health Ruth Kirschstein National Research Service Award Predoctoral Fellow. She was recognized by the Robert Wood Johnson Foundation as an Interdisciplinary Research Leader.

WHEN

Monday, November 18, 2019
1:30p.m. - 2:30p.m. (ET)

LOCATION

NIH Main Campus
Bethesda, MD
Wilson Hall,
Building 1, 3rd Floor



National Institutes of Health
Tribal Health Research Office

[THRO Home](#)

[TAC](#)

[THRCC](#)

[Tribal Consultations](#)

[Research and Funding](#)

About the Staff

[DPCPSI](#) » [THRO](#) » [About Us](#) » [About the Staff](#)



David R. Wilson, Ph.D.
THRO Director



Juliana Blome, Ph.D.
Assistant Director



Edmund (Ted) Keane, MSPH
Health Science Policy Analyst



Tori Mends-Cole, MA
Health Science Policy Analyst



Maria Jamela R. Revilleza, Ph.D.
Health Science Policy Analyst



Shawn M. Thomas, MPH
Health Science Policy Analyst

What is down the road in 2020

- Meeting the Strategic Plan
- Continue to educate scientists about our communities
- 2018 Research Portfolio
- Continuing our efforts with the Institutes and Center at the NIH in Tribal Health Research

dave.wilson2@nih.gov

