

Tribal Health Research Office

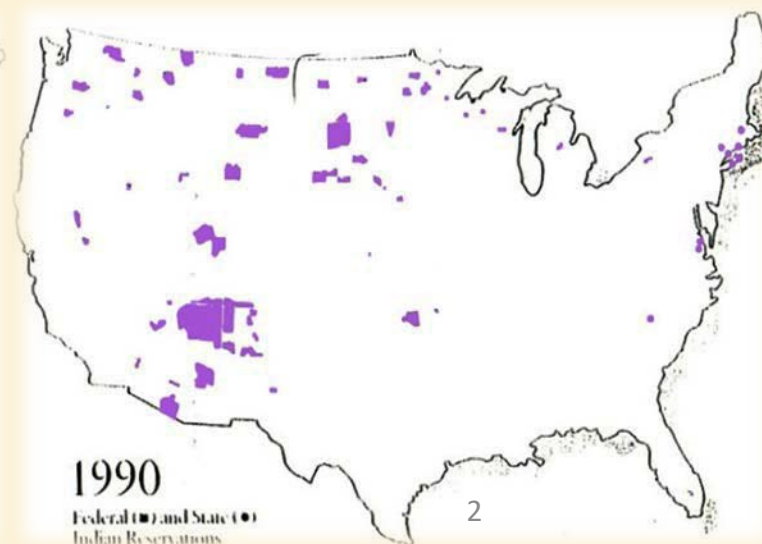
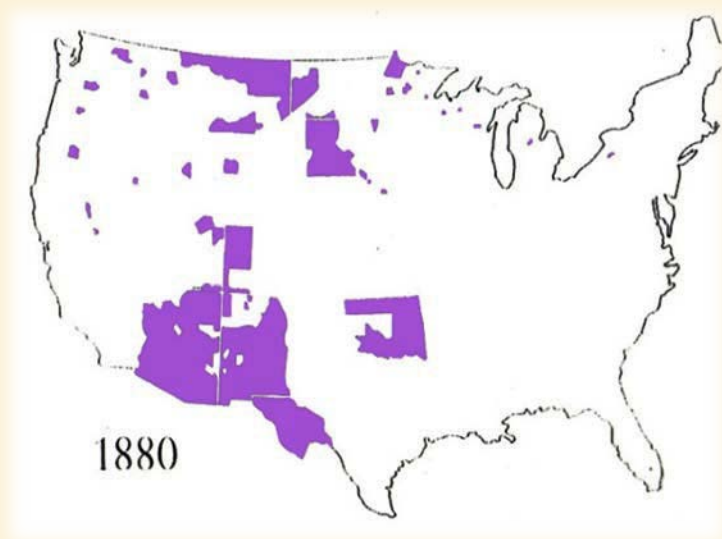
Update and Input

David R. Wilson, PhD.

Council of Councils
January 26, 2018



American Indian Reservations





Federal Trust Responsibility

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



567 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”



2010 HHS Tribal Consultation Policy

OBJECTIVES

1. To formalize the Administration's policy that **HHS seek consultation and the participation of Indian Tribes in the development of policies and program activities that impact Indian Tribes.**
2. To establish a minimum set of requirements and expectations with respect to consultation and participation throughout HHS management, the Office of the Secretary (OS) Division, and Regional levels.
3. The need to consult may be identified by the Department or by an Indian Tribe(s). Any time the Tribe(s) or the Department identifies a critical event the Department may initiate any necessary consultation in accordance with this policy.
4. **To identify events and partnerships that HHS would participate with Indian Tribe(s)** and Tribal/Indian Organizations that establish and foster partnerships with HHS which complement and enhance consultation with Indian Tribes.
5. To promote and develop innovative consultation methods with Indian Tribes in the development of HHS policy and regulatory processes.
6. To uphold the responsibility of HHS to consult with Indian Tribes on new and existing health and human service policies, programs, functions, services and activities that have Tribal implications.
7. To charge and hold accountable each of the HHS Operating Division Heads for the implementation of this policy.
8. To be responsive to requests by an Indian Tribe(s) request for consultation and technical assistance in obtaining HHS resources.
9. To charge the HHS Operating Divisions with the responsibility for enhancing partnerships with Indian Tribes which will include, requests for technical assistance, access to programs and resources, as well as collaborating with Tribal subject matter expertise.
10. **To provide a single point of contact within HHS and its Operating Divisions for Indian Tribes at the highest level** which would have access to the IOS, the Deputy Secretary, and Operating Division Heads. The Principal Advisor for Tribal Affairs and the Division Tribal points of contact will be responsible for compliance with this policy and ensuring timeframes identified in section 9 are met.

Year 1 of THRO



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 Tribal Health Research Office functions are to:

- coordinate tribal health research-related activities across NIH
- serve as a liaison to and NIH representative on tribal health related committees and working groups
- coordinate and support the NIH [Tribal Advisory Committee](#)
- collaborate with NIH Institutes and Centers on the development of reports on tribal health topics
- manage information dissemination related to tribal health research coordination
- convene trans-NIH committees, workshops, meetings and other activities related to tribal health research and scientific priorities
- coordinate with NIH Institutes and Centers (ICs) to leverage resources or develop initiatives to support tribal health research
- convene at least yearly Tribal Consultation sessions



Early activities of the Tribal Health Research Office

1. Tribal Advisory Committee (TAC) provides recommendations on NIH activities in tribal communities
Sept 14-15, 2017 in person meeting focused on Data Sharing and Data Ownership
March 13-14, 2018, NIH campus
2. Trans-NIH working group: Tribal Health Research Coordinating Committee (THRCC)
3. THRO Strategic Plan Development
4. AI/AN Research Portfolio



TAC Members, Technical Advisors and THRO Director Dr. Wilson

Front row (from l to r): Alison Ball*, Denise Dillard*, Beverly Cook*, Chester Antone*, Walter Phelps*, David Wilson. **Middle row (from l to r):** Marcia O'Leary, Kori Novak, Breannon Babbel, Lynn Malerba*, Liana Onnen*, Debra Danforth*, Donna Galbreath*, Christy Duke, Karol Dixon, Deana Around Him. **Back row (from l to r):** David Foley, L. Jace Kilsback*, Joshua Saxon-Whitcrane*, Jeromy Sullivan*, Lisa Rey Thomas, Malia Villegas*, Renee Robinson, Bobby Saunkeah*, Michael Peercy. **Not pictured:** Allison Barlow, Lyle Best, Harold Frazier*, Aaron Payment*, and Teshia G. Arambula Solomon (TAC members*)



DPCPSI » THRO » TAC

NIH Tribal Advisory Committee (TAC)

The TAC is advisory to the NIH, and provides a forum for meetings between elected Tribal officials (or 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.

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.

Additional Info

- [Charter](#)
- [Members](#)
- [Meetings](#)
 - [Mar. 9-10, 2017](#)
 - [Sep. 15-16, 2016](#)
 - [Feb. 25-26, 2016](#)
 - [Sep. 29-30, 2015](#)
- [Monthly Call Agendas](#)



Trans-NIH Tribal Health Research Coordinating Committee (THRCC)

- Drafting the first AI/AN portfolio Analysis and Strategic Plan for THRO
- ICs and THRO collaborations
 - NHGRI-Genomics initiative
 - NIMH attended the 1st Tribal Leaders Behavioral Health Summit; Tulsa, OK
 - NIMHD and TECs
 - Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers (R01) [PAR-17-484](#)
 - Collaborative Minority Health and Health Disparities Research with Tribal Epidemiology Centers (R21) [PAR-17-483](#)
 - NIGMS-NARCH
- Student Training and Development
 - Trans-NIH effort



Strategic Planning Process

- NIH Tribal Advisory Committee's priority list
 - Tribal Health Research Coordinating Committee
 - National Tribal Consultation in Alaska in June 2017
 - Conferences and workshops, 15
 - 5 Strategic priorities
-
- Tribal Health Research Office Strategic Plan (FY2018-2022) Request for Information, published 12/4/17:closes 2/4/2018
<https://grants.nih.gov/grants/guide/notice-files/NOT-OD-18-110.html>



Strategic Priority 1 - Enhance Communication and Coordination: Greatly increase the bidirectional flow of information to and from tribal communities, and the NIH ICOs, and other relevant stakeholders.

Strategic Objective 1.1: Facilitate NIH Tribal Advisory Committee (TAC) input to NIH research activities and promoting the health of AI/AN communities.

Strategic Objective 1.2: Promote dialogue with tribal communities, tribal leaders, and tribal-serving organizations about NIH research activities and the health of AI/AN communities.

Strategic Objective 1.3: Gather input from tribal communities, tribal leaders, and tribal-serving organizations about the gaps in health research for AI/AN populations.

Strategic Objective 1.4: Support trans-NIH communication to coordinate AI/AN health needs with ICO research priorities.

Strategic Objective 1.5: Increase trans-NIH communication with the broader scientific community about AI/AN health needs and ICO research activities.

Strategic Priority 1 - Enhance Communication and Coordination: Greatly increase the bidirectional flow of information to and from tribal communities, and the NIH ICOs, and other relevant stakeholders.



Genetics Workshop at University of New Mexico Comprehensive Cancer Center, August 2017



Strategic Priority 2 - Build Research Capacity: Coordinate efforts to increase research capacity in AI/AN communities at all levels, including but not limited to e.g., grant writing, professional development and the amount of research conducted. The ultimate goal is to build a strong, coordinated community of AI/AN researchers and expand scientific knowledge to improve the health of AI/AN communities.

Strategic Objective 2.1: Engage the diverse range of research expertise within AI/AN tribal organizations, tribal colleges, and AI/AN researchers.

Strategic Objective 2.2: Support innovative research that respects AI/AN diversity through: AI/AN research and outcome priorities; flexible models of measurement and assessment; identifying and resolving research barriers; and supporting research training opportunities to at all levels of education.

Strategic Objective 2.3: Build institutional capacity to support AI/AN diversity in health research at NIH Program, Review, and Grants Management level.

Strategic Priority 2 - Build Research Capacity: Coordinate efforts to increase research capacity in AI/AN communities at all levels

- NIH summer interns
- National Indian Health Board policy fellows
- National Congress of American Indian fellows
- Association of American Indian Physicians Students





Strategic Priority 3 - Expand Research: Diversify the NIH research portfolio directed at health issues in tribal communities. Building research must go beyond the investigators and look to the portfolio of the agency. This will mean not only an examination of the existing research portfolio in American Indian/Alaska Native (AI/AN) communities, but also an examination – and subsequent intentional action – to address those gaps in the portfolio to explore emerging and increasing areas of research that are important to improving the health of these communities.

Strategic Objective 3.1: Develop institutional platform for understanding of AI/AN health research backgrounds, challenges, and needs, as well as generate new research opportunities for tribal communities.

Strategic Objective 3.2: Develop opportunities for AI/AN investigators including number of NIH-sponsored basic, clinical, behavioral, and translational research projects focused on AI/AN health. Support developmental programs for AI/AN scientists in biomedical research and track that progress within the NIH.

Strategic Objective 3.3: identify the challenges and opportunities to increasing AI/AN participation in biomedical research, including historical context, trust, and cultural appropriateness.

Strategic Priority 3 - Expand Research: Diversify the NIH research portfolio directed at health issues in tribal communities.



ECHO & THRO site visit
to Navajo Nation





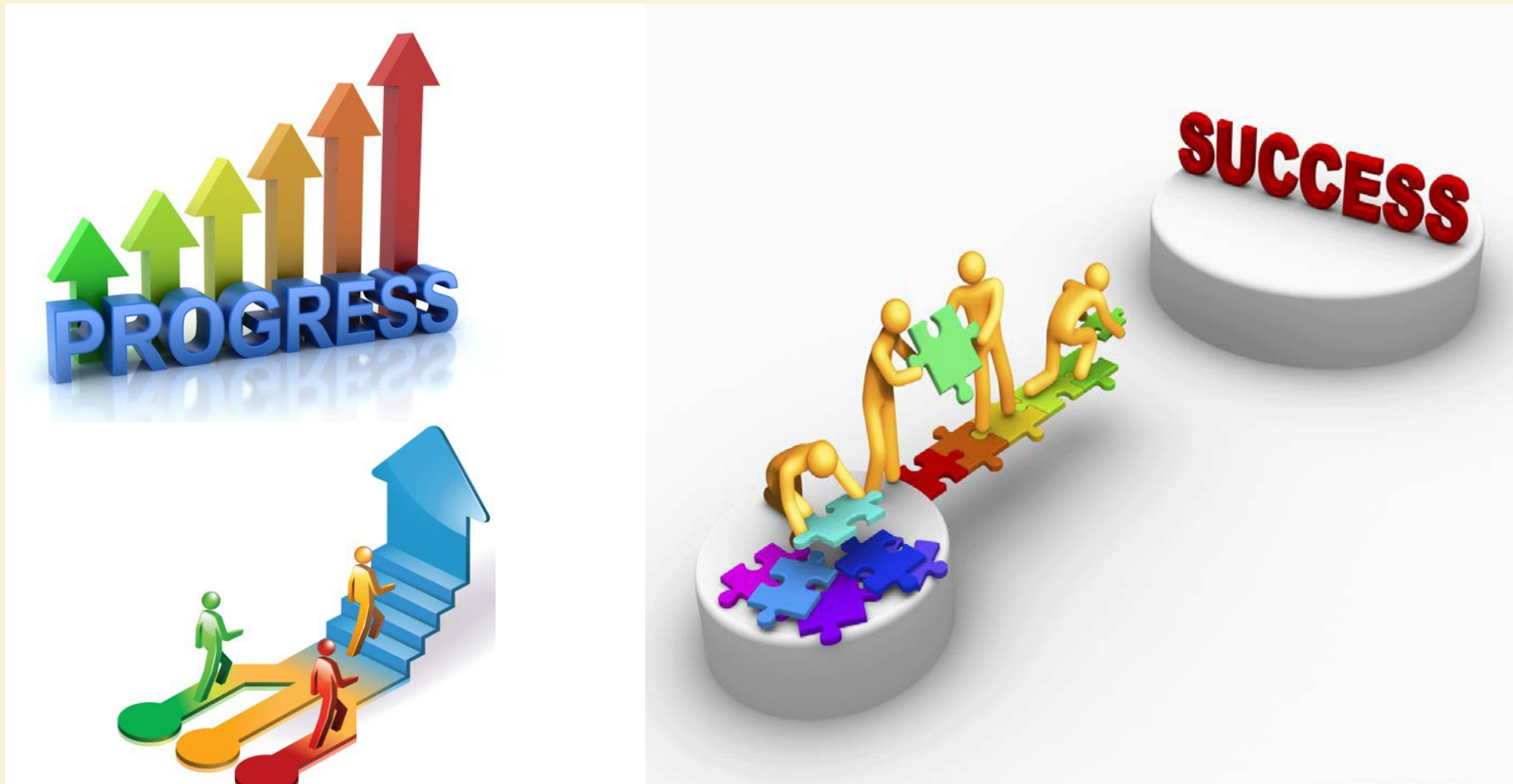
Strategic Priority 4 - Evaluate Progress: Establish a set of mutually agreeable measurements that allows stakeholders to determine if, and to what degree, Tribal Health Research Office (THRO) is successful in achieving strategic priorities and objectives.

Strategic Objective 4.1: Develop processes and metrics to measure program development within NIH, in public arenas, and with AI/AN communities.

Strategic Objective 4.2: Gather input and feedback from AI/AN communities in measurement and evaluation process.

Strategic Objective 4.3: Evaluate the NIH staff engagement in training and ability to address AI/AN research needs.

Strategic Priority 4 - Evaluate Progress: Establish a set of mutually agreeable measurements that allows stakeholders to determine if, and to what degree, Tribal Health Research Office (THRO) is successful in achieving strategic priorities and objectives.

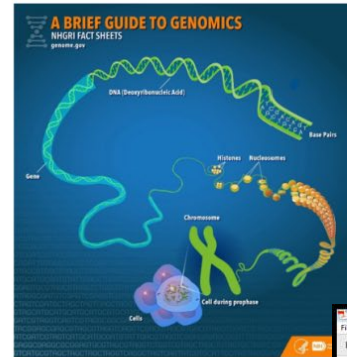
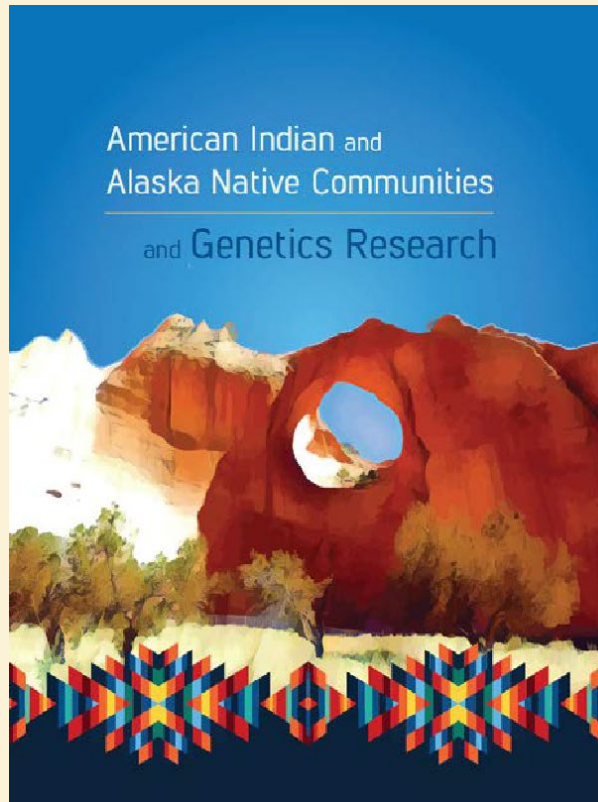




Strategic Priority 5 – Address cross-cutting areas of Cultural Competency and Community Engagement: Ensure that the NIH employs a consistent, respectful approach when collaborating with tribal communities to achieve each of the previous four strategic priorities.

Strategic Objective 5.1: Strengthen the relationships and collaborative partnerships between the NIH and AI/AN communities by education, cultural competency, and communication both intramurally and extramurally.

Strategic Priority 5 – Address cross-cutting areas of Cultural Competency and Community Engagement: Ensure that the NIH employs a consistent, respectful approach when collaborating with tribal communities to achieve each of the previous four strategic priorities.



1 image from <https://www.genome.gov/18016863/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 throughout your lifetime. These instructions are passed down from your biological mother and father. Half of your genome comes from your mother, and half from your father. These passed-down instructions influence such traits as your height, eye color, and whether or not you are protected

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 small differences, or genetic variations, result in the differences in our physical traits. They are what make you unique.

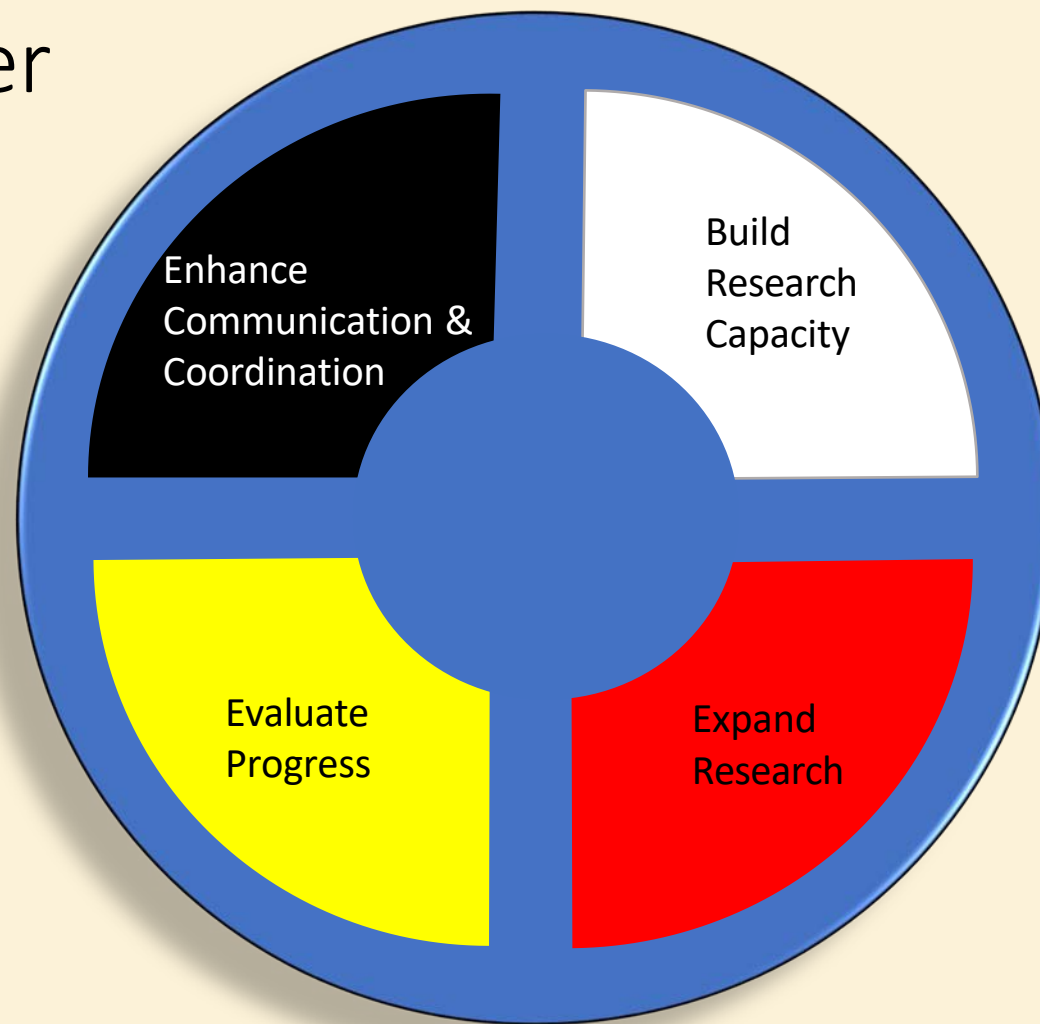
However, your genome is only part of what determines your health and traits – your genes and the environment. Sometimes changes in the genome will definitely result in a certain disease. These include such diseases as Huntington's disease, cystic fibrosis, or sickle cell anemia. But most of the time, many genes act together and can be influenced by the environment. These

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?



How it all comes together





Comments and Questions