

## Maintaining Data Sovereignty in Indian Country

This course will provide students at tribal colleges with the information they require to start their own inquiries about Indigenous Data Sovereignty and Governance. The class emphasizes Indigenous Genetic research in relation to (1) sovereignty, (2) stakeholders, and (3) governance. The goal is that they students learn how to implement both sovereignty and governance in their genetics research with their communities.

The book *Indigenous Data Sovereignty and Policy* discusses Indigenous data narratives. Which is also discussed in the first 10 minutes of the podcast “tribal people doing tribal research native perspective” from Salish Kootenai College. Indigenous communities will have to push boundaries to participate in genetics research. If “researchers and IRBs do not change their policies... these populations will likely continue to be excluded from a majority of research studies and left with less access to resources and potential benefit from genetic research participation.”(Garrison, 2013). This module takes the stance that Indigenous communities are now being called to design, collect, and analyze their data. It’s time for the beginning of a world fueled by Indigenous knowledge/medicine in the new world.

The course strives for authenticity, to present both sovereignty and governance of genomics through the American Indian perspective. This is an introductory course that will give them the knowledge they require to take the next step towards careers in genomics where they implement indigenous research and data management.

The students will explore four main questions in the course:

1. Who provides the instructions?
2. What are the boundaries to push in Indigenous genomics?
3. Who is telling the story of Indigenous Nations?
4. What can Indigenous Nations do to tell their own genomics stories?

Guided by the book *Indigenous data sovereignty : toward an agenda* and *Indigenous Data Sovereignty and Policy* three directions that Indigenous nations can go to control their research and data:

- (1) the power to decide to participate,
- (2) data should reflect the ideologies of the Native communities that share the data, and,
- (3) it is imperative that Indigenous nations gain capacity to control their data.

If Indigenous Nations have no capacity to control the data, then it is open to misuse. Snipp asserts that until recently it was unclear how Native nations could acquire the means. In addition, “...the cost and diffusion of this knowledge have declined dramatically...” (Snipp (2016)).

To implement Indigenous data sovereignty in the field of genetics, communities should consider working with research councils, their local and national government to develop guidelines. Examples of this include the guidelines developed by the Aboriginal and Torres Strait Islander Peoples and communities.

**Important text for the course:**

Text about best practices in field of Indigenous sovereignty and governance:

*Indigenous data sovereignty: toward an agenda*, eds., Tahu Kukatui, John Taylor, Research monograph (Australian National University. Centre for Aboriginal Economic Policy Research); no. 38.

*Indigenous Data Sovereignty and Policy*, eds., Maggie Walter, Tahu Kukatui, Stephanie Russo Carroll and Desi Rodrigues-Lonebear (2020) Routledge

Carroll, S.R., Rodriguez-Lonebear, D. and Martinez, A. (2019) Indigenous Data Governance: Strategies from United States Native Nations. *Data Science Journal*, 18(1), p.31. DOI: <http://doi.org/10.5334/dsj-2019-031>

Carroll, S.R., Rodriguez-Lonebear, and Martinez, A POLICY BRIEF Indigenous Data Sovereignty in the United States (<https://www.ncai.org/resources/resolutions/support-of-us-indigenous-data-sovereignty-and-inclusion-of-tribes-in-the-development-of-tribal-data>)

Carroll, S.R., et al. (2020) The CARE Principles for Indigenous Data Governance. *Data Science Journal*, 19(1), p.43. DOI: <http://doi.org/10.5334/dsj-2020-043>

Lovett, Ray, Vanessa Lee, Tahu Kukatui, Stephanie Carroll Rainie, Jennifer Walker. 2019. Good Data Practices for Indigenous Data Sovereignty, in Angela Daly, Kate Devitt, & Monique Mann (Eds.), *Good Data*, Amsterdam: Institute of Network Cultures Inc. ISBN 978-94-92302-27-4. [http://networkcultures.org/wp-content/uploads/2019/01/Good\\_Data.pdf](http://networkcultures.org/wp-content/uploads/2019/01/Good_Data.pdf)

Rebecca Tsosie, (2019) Tribal Data Governance and Informational Privacy: Constructing "Indigenous Data Sovereignty", 80 *Mont. Law. Rev.* 229.

National Health and Medical Research Council, *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders* (2018), Commonwealth of Australia: Canberra.

Text for current issues in Indigenous sovereignty and governance:

Laura Matson, et al. (2021) Transforming research and relationships through collaborative tribal-university partnerships on Manoomin (wild rice), *Environmental Science & Policy*, Volume 115, ISSN 1462-9011, <https://doi.org/10.1016/j.envsci.2020.10.010>.

Begay, Rene (2020) *Weaving the Strands of Life (Iiná Bitł'ool): History of Genetic Bit 'ool): Research Involving Navajo People*

Garrison, N.A. (2013) Genomic Justice for Native Americans: Impact of the Havasupai Case on Genetic Research. *Sci Technol Human Values*; 38(2): 201–223. doi:10.1177/0162243912470009

Garrison N.A., et al. (2019), Genomic Research Through an Indigenous Lens: Understanding the Expectations, Annual Review of Genomics and Human Genetics 2019 20:1, 495-517

### **Entities to be aware of:**

UN Declaration on the Rights of Indigenous Peoples (UNDRIP),  
United States Indigenous Data Sovereignty Network  
Indigenous Data Governance CARE Principles  
The Native BioData Consortium  
National Congress of American Indians  
Navajo Nation's moratorium on Genetic Research  
Columbia River Fishing Coalition  
Salish Sea Research Center

### **Podcasts:**

<https://podcasts.apple.com/us/podcast/22-tribal-people-doing-tribal-research-native-perspective/id1512551396?i=1000493601755>

<https://soundcloud.com/user-817103038/episode-1-feat-dr-julie-lucero>

### **1.1 Indigenous Data Sovereignty Concepts**

To begin to understand data, it is important to begin to understand how data is collected. As a scientist by training, I turn to the Oxford definition of the term research, “Research is a systematic investigation into and study of materials and sources in order to establish facts and reach new conclusions.” As an Indigenous person, I understand that “...research and the collection of data are not foreign concepts in the Indigenous world...” (Carroll, Rodriguez-Lonebear, and Martinez (2019)). Indigenous peoples “have always been data creators, data users, and data stewards. Data were and are embedded in Indigenous instructional practices and cultural principles” (NCAI 2018, p. 1).

It is also important to understand the types of data that are collected and considered ‘important’ by stakeholders. A stakeholder is likely going to be someone who is proposing and designing and also likely funding the research project. Based on results from Garrison et al., 2019, Indigenous research defines the participants as valuable stakeholders (see table 2).

There are two kinds of research, (1) qualitative research involves collecting and analyzing non-numerical data (e.g., text, video, or audio) to understand concepts, opinions, or experiences. And, (2) quantitative research is the process of collecting and analyzing numerical data. Depending on who is doing the research, one or the other is used to tell the research story. Before research is started, it is also important to know who has the right to research data and who has interest in the data (Walter, Maggie, and Andersen, 2013). This is where “sovereignty” becomes important. Sovereignty is a political theory where an individual or a group of people have the full right and power to govern itself. They do so without any interference from outside sources. In the U.S., tribal sovereignty refers to the right of American Indians and Alaska Natives to govern themselves. For example, the U.S. Constitution recognizes Native American tribes as distinct governments. Sovereignty for tribes includes the right to establish their own

form of government, determine membership requirements, enact legislation and establish law enforcement and court systems.

Next, we must discuss Indigenous data sovereignty. “Indigenous data sovereignty is best understood within the context of United States Federal Indian law and the construction of tribal sovereignty, as well as international human rights law and the construction of the rights of Indigenous peoples (Tsosie (2019)). Indigenous data sovereignty is derived from tribes’ inherent right to govern its people, land, and resources (United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP); Taylor and Kukutai 2015).

## **2.1 Data misuse:**

To delve into the question, “Who provides the instructions? Let’s begin with a conversation about Albert Scherr. Dr. Scherr is a skeptic of genetic genealogy. He is a professor at the University of New Hampshire Franklin Pierce School of Law and a nationally recognized authority on forensic DNA evidence.

Dr. Scherr says, “...the information that is in your genes far exceeds any other repository of information that exists about your life... [and includes answers to] are you predisposed to alcoholism, schizophrenia,... [and] are there ways [the government] can exploit this information?”

*Examples of how this has already happened:*

In the 1990s, researchers from Arizona State University drew blood from members of the Havasupai, a tribal nation of fewer than 1,000 people. The stated purpose was to investigate the genetic cause of diabetes, an illness that affects the Havasupai in high numbers. Blood was given on the premise that the tribe would see some medical insight in return for their contribution. In the years that followed, however, the diabetes research program stalled while the blood samples were shared with other researchers to investigate subjects to which the tribe had not consented. Not only did the researchers not find anything about type 2 diabetes, they studied their genetic data, without consent, schizophrenia, inbreeding, and migration. The work was published in 2004. The scientists’ conclusions challenged the thousands-year-old Havasupai origin beliefs also shared by the Yuma and Mojave (Garrison et al., 2013).

*Examples of how Native Nations have preemptively protected Indian Country:*

The Navajo Nation tribal government banned DNA studies in 2002 to prevent the misuse of its members' genetic material.

## **2.2 Examples of research centers that implement data sovereignty and governance:**

The conception of the Salish Sea Research Center (SSRC) at Northwest Indian College (NWIC), was focused on the scientific research potential of NWIC, with the completion of a state-of-the-art marine science laboratory. The SSRC has created opportunities at NWIC for both students and faculty researchers in STEM fields to produce quality research products (Pietsch and Arnold 2017; Peacock et al. 2018).

The SSRC conducts its research in an open and transparent manner with ample opportunity for collaboration with the Lummi tribal members. The director and co-director have weekly interactions with employees of the Lummi Indian Business Council (LIBC). These discussions are the foundation for the research currently underway at the research center. The director has established an excellent working agenda that addresses the top priorities of Indian Country through interactions with Lummi Natural Resources. The Coast Salish Institute (CSI), also located at NWIC, identifies cultural traditions and ceremonial practices of the Lummi people that may influence management design and implementation.

The Columbia River Fishing Coalition integrates traditional ecological knowledge with Western Science, Common ideologies coming together solve community-based problems with tools from both Western science and Indigenous Knowledge. The work is guided by the Nez Perce, Umatilla, Warm Springs, and Yakama tribes. Salmon principles are outlined in Wy-Kan-Ush-Mi Wa-Kish-Wit (Spirit of the Salmon). Tribal salmon plans address recommended restoration actions in every phase of the salmon's life cycle from stream to ocean and back.

The Native BioData Consortium is the first 501(c)(3) nonprofit research institute led by Indigenous scientists and tribal members in the United States. As a biorepository (or "biobank"), the Native BioData Consortium ensures that advances in genetics and health research benefit all Indigenous people.