### <u>PROTECTIONS</u> <u>FROM BIG DATA CURRENTS:</u> TRIBAL REPOSITORIES

#### JOSEPH M YRACHETA

(P'URHEPECHA) MS PHARMACOGENOMICS, PHD © EXECUTIVE DIRECTOR NATIVE BIODATA CONSORTIUM



Tribal data sovereignty improves health and economic sharing in Indian Country.

**Today protect what is ours** 



## A Model of Indigenous Data Sovereignty



# Native BioData



Joseph Yracheta, P'urhepecha

WWW.NATIVEBIO.ORG

## Our Policy Work

- Chief's Committee to Secure and Safeguard Sovereignty, possession over Data, Genomics, Al and their uses" Anishinabek Nation Grand Council Assembly, Red Rock Indian Band, June 2022
- "Preventing Evasion of Tribal Nation Data Sovereignty in the Health Research Sector by Means of Technological Modernization in an Unsettled Regulatory Frontier" National Congress of American Indians, #SAC-22-026, November 2022
- *"Tribal Data Sovereignty and Research Governance Plan"* Cheyenne River Sioux Tribe, May 2023
- "Oceti Sakowin Wóophe of Big Data, Omics, and Artificial Intelligence Technologies Policy Guidance" Oceti Sakowin Treaty Conference (Seven Council Fires of the Sioux) December 2022 (pending)







## Data to Recreate and Predict

How is Open Data useful when there was Data Bias in the past 40 years & worsening today?

In 2019, the National Institute of Standards and Technology ("NIST") published a report analyzing the performance, across races, of 189 facial recognition algorithms submitted by 99 developers, including Microsoft, Intel, Idemia, and other major tech and surveillance companies. Many of these algorithms were found to be between 10 and 100 times more likely to misidentify a Black or East Asian face than a white face. In some cases, American Indian faces were the most frequently misidentified. Most algorithms were substantially less likely to correctly identify a Black woman than a member of any other demographic. To understand the reasons for these disparities, it helps to understand the basics of how facial recognition technology works.

Machine Learning will scrape data and follow bread crumbs making PRIVACY harder to achieve: Anti 4<sup>th</sup> & 6<sup>th</sup> amendment? Illegal Search and Seizure?

## The Hansel & Gretel Effect The hidden trail of digital breadcrumbs

#digitalbreadcrumbs @danpankraz "Weapons of Math Destruction: How Big Data Increases Inequality and Threatens Democracy", Cathy O'Neil, Book 2016

### Regulate and avoid The Hoover:

There's a Wild West of Data Capture & a Disrespect of Tribal Regulation (Regulations are Data too)



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#### **Tribal Approvals for Publications**

IHS IRB and tribal approvals: The primary author will first send the paper to the co-authors for their input. All Strong Heart Study manuscripts must have IHS IRB and tribal approvals. When the primary author feels the paper is ready for IHS IRB and tribal review, he/she should submit required files to the contact person of each of the three field centers (see below) with the clear designation that the paper is being sent for IHS IRB and tribal review.

Requests can be submitted online using this link : SHS Tribal Approval Request Form

Files needed for obtaining IHS IRB and tribal approval: 1) an early version of the manuscript, 2) a lay summary that includes a sentence indicating the time of data collection (SHS study phases), and 3) the name of the intended journal. The three field centers will process the IHS IRB and tribal review within 90 days. Contact information:



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