

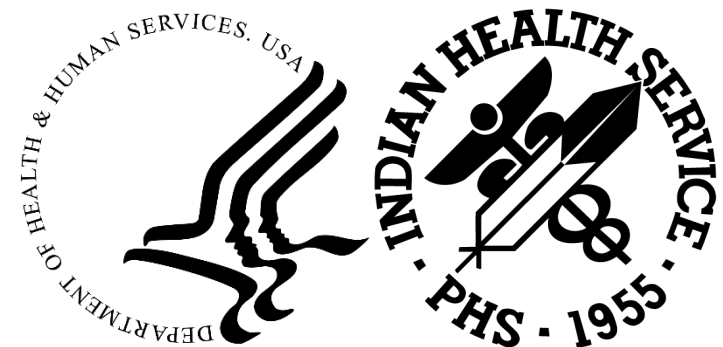
# The IHS Health Information Technology (IT) Modernization Program

## Data Modernization at IHS

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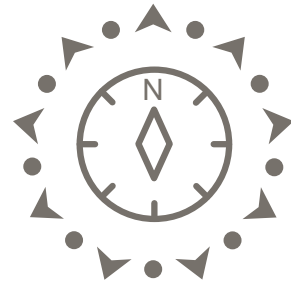
MITCHELL THORNBRUGH, CIO

SEPTEMBER 2023



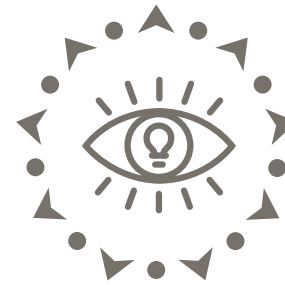
# Indian Health Service

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## IHS Mission

To raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level

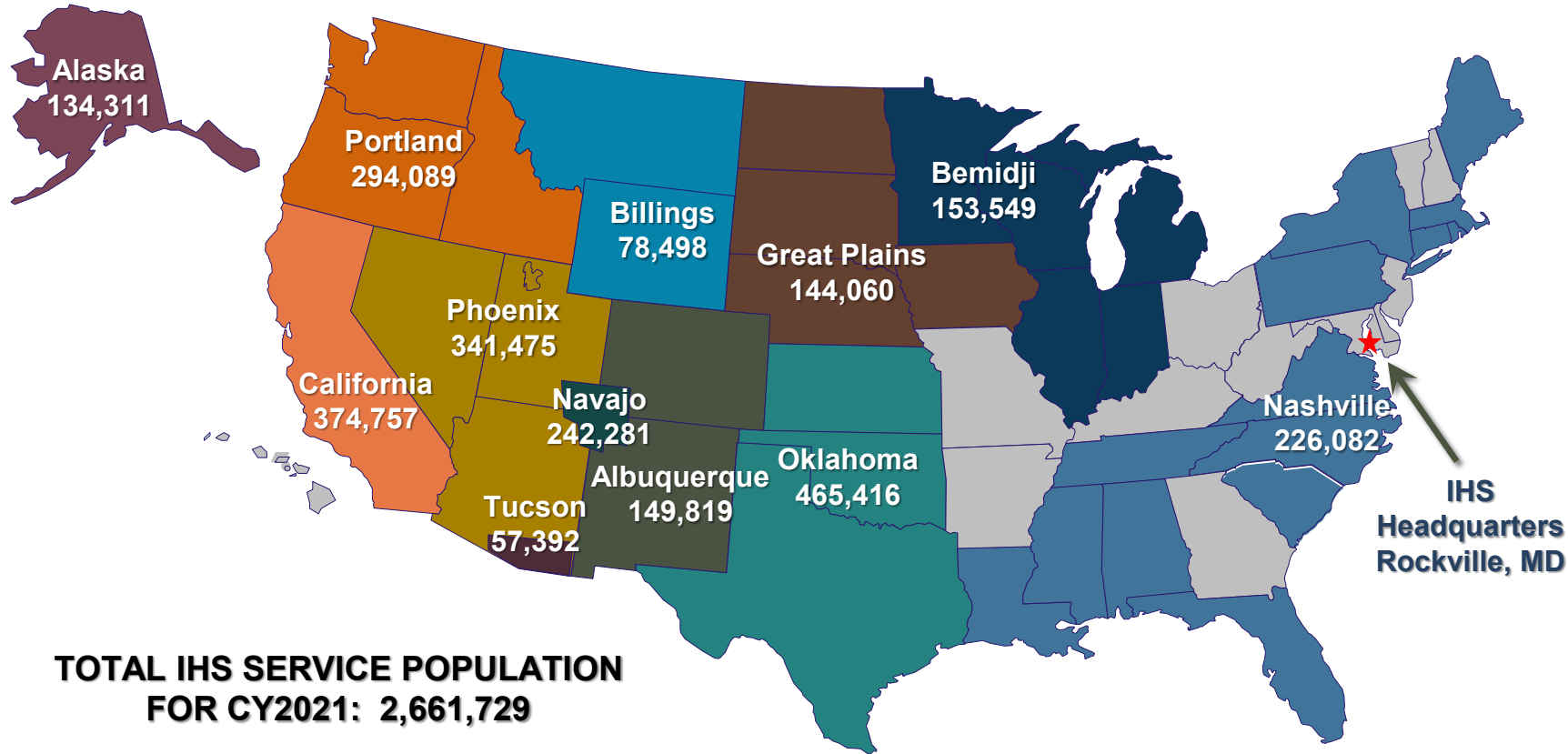


## IHS Vision

Build healthy communities and quality health care systems through strong partnerships and culturally responsive practices



# The Indian Health System



- IHS administers its operations through 12 Area Offices
- The Indian health system supports healthcare delivery in 37 states including Alaska
- The Indian health system is comprised of facilities managed by IHS, tribal, and urban Indian organizations

# Health IT Modernization Timeline

2018 - 2019

## Research

- Health and Human Services (HHS)/IHS Modernization Research Project Report with three modernization approaches
- U.S. Government and Accountability Office (GAO) Report on Critical Legacy Systems
- HHS Office of the Inspector General health IT reports released

2020 - 2021

## Plan

- Listening Sessions on modernization approaches
- [Decision memo](#) announcing plans to replace Resource and Patient Management System (RPMS)
- Establish Program Management Office (PMO)
- Virtual Industry Day and Requests for Information (RFI) from industry
- Acquisition strategy

2022 - 2024

## Buy & Build

- Office of Information Technology (OIT) Division of Health IT Modernization and Operations (DHITMO) creation
- Request for Proposal (RFP) for EHR solution vendor & integrator
- Extensive proposal evaluation and product demonstrations
- Contracts for PMO and Organizational Change Management (OCM) support
- EHR solution award pending
- Start of system build
- Human Capital Planning/Workforce Analysis

2025 +

## Train, Deploy, Operate

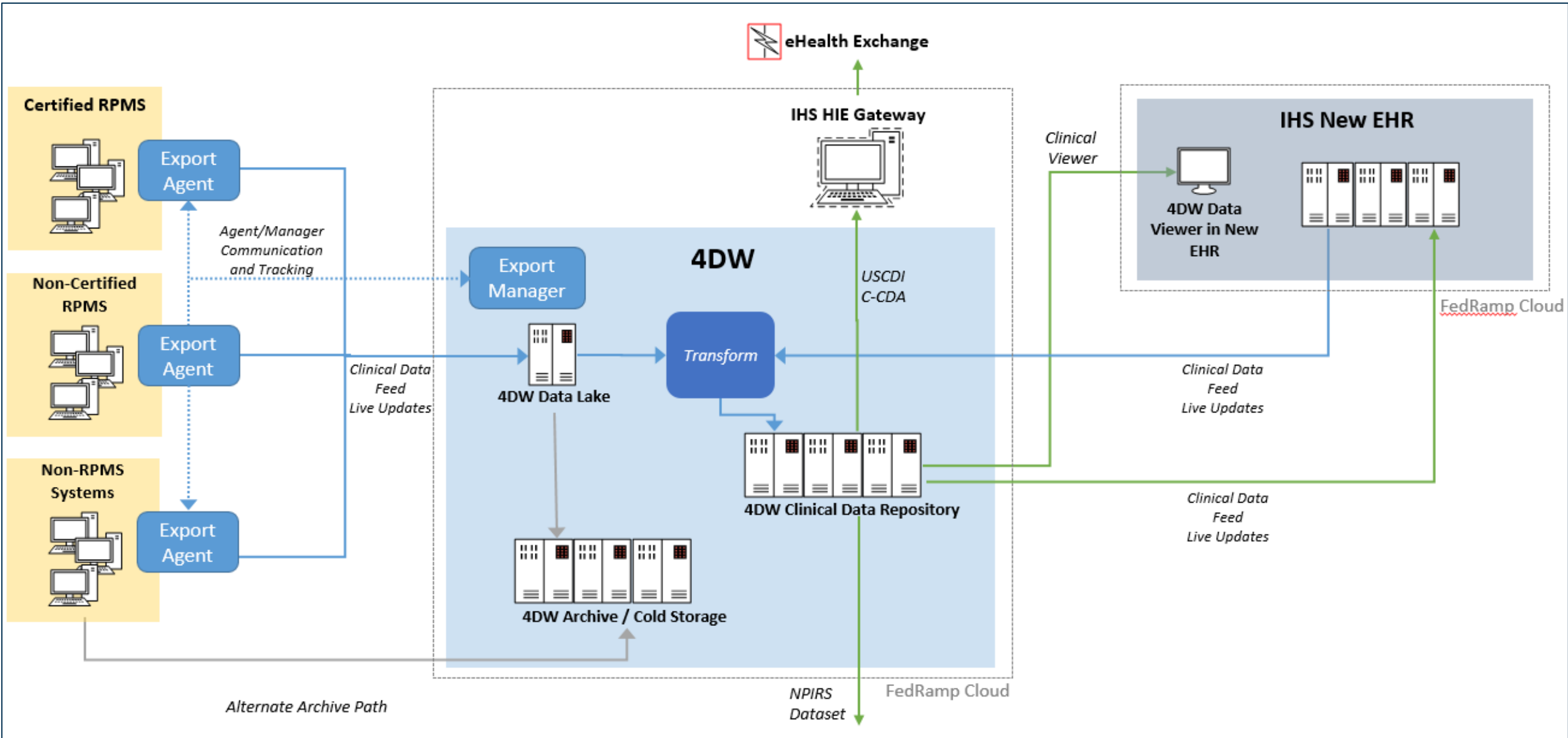
- Focus on Organizational Change Management
- Local infrastructure assessment and mitigation
- User training
- Multi-year rollout in cohorts, across IHS, Tribal, and Urban Indian Organizations (I/T/U)



# Goals of Effective Health Data Management

- Successful data migration from legacy systems destined for retirement
- Accuracy and availability of patient record data for care, care coordination, and revenue cycle management
- Interoperability – within and external to the broader organization
- Data privacy and security
- Availability of data for appropriately governed analytics – local, regional, national
- Preservation of health records – for the patient and the care organization

# Prototype Data Architecture for Modernization



# Health Disparity & Equity

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## HEALTH DISPARITY

- A health difference closely linked with economic, social, or environmental disadvantages based on
  - Race or ethnic group
  - Religion
  - Socioeconomic status
  - Gender
  - Age
  - Physical and mental disabilities
  - Sexual orientation or gender identity
  - Geographic locations

## HEALTH EQUITY

- An underlying commitment to reduce—and ultimately eliminate—disparities in health and in its determinants through
  - High health standards for all individuals
  - Increased attention to those at the greatest risk based on social conditions



# Modernized Data Benefits

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- Increased access to care
- Access to data in and out of the IHS network
- Analysis of data to improve AI/AN community health
- Improved health outcomes due to data drive clinical practices





# Federal Data Sharing Obligations to Tribes

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Aila Hoss, JD

Associate Professor

Indiana University McKinney School of Law





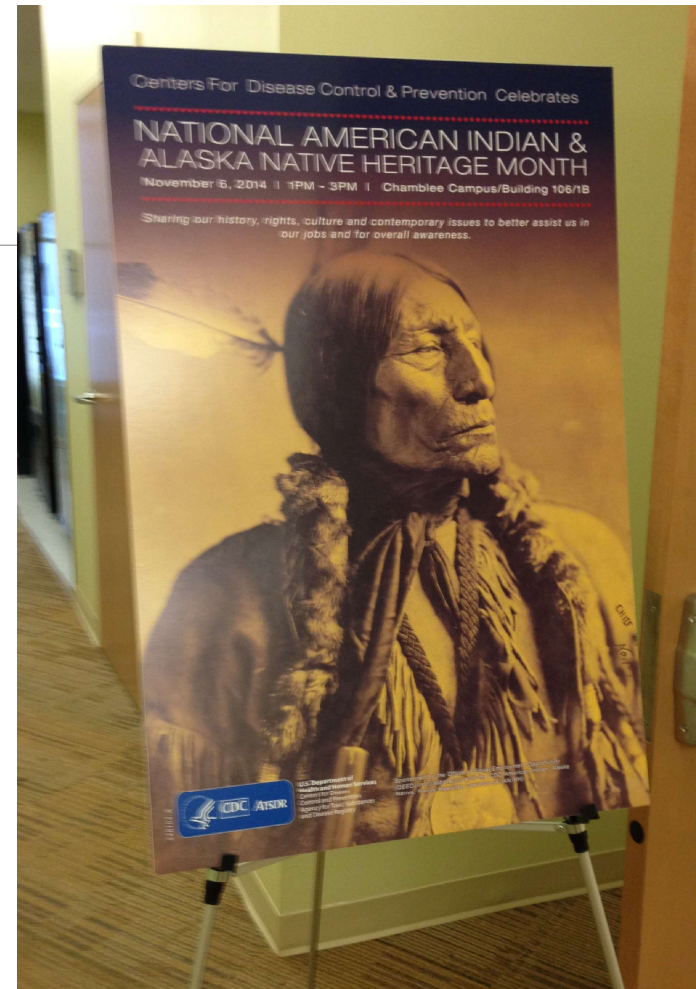
Glad to be here!



my assistant




# Acknowledgments



# Our Time Together

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- Data Sharing Laws of General Applicability
  - Tribal-Specific Requirements
  - Trust Responsibility
  - Enforcement
- 

# Considerations

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**Tribal Data Sovereignty:** entire life cycle

**Process:** for making a request

**Timing:** how fast is the data provided

**Format:** what format is the data

**Completeness:** does it include PHI

**Direct Access:** to the system

**Equitable Access:** compared to states


# Data Sharing Laws of General Applicability

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# Freedom of Information Act (FOIA)

## 5 U.S.C. § 552

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- Enacted by Congress in 1966
  - Applies to full or partial records held by executive agencies
  - Applies to all records not subject to an exemption or exclusion
  - Does not require the release of information in the most convenient format
  - Must a response (not fulfill the request) w/in 20 days
  - Enforcement: appeal; judicial review; actions against individual employees
- 




# FOIA Exemptions and Exclusions

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## ■ Exemptions

1. Classified national defense and foreign relations information
2. Internal agency rules and practices
3. Information that is prohibited from disclosure by another law
4. Trade secrets and other confidential business information
5. Inter-agency or intra-agency communications that are protected by legal privileges
6. Information involving matters of personal privacy
7. Certain information compiled for law enforcement purposes
8. Information relating to the supervision of financial institutions
9. Geological information on wells

■ **Exclusions:** certain sensitive information related to law enforcement and national security



# New York Times v. CDC (2020)

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- NYT submitted a FOIA request to the CDC requesting data showing the impact of CV-19 on low-income and minority communities
- CDC denied the request. NYT litigated.
- “Black and Latino people have been disproportionately affected by the coronavirus in a widespread manner that spans the country, throughout hundreds of counties in urban, suburban and rural areas, and across all age groups.”

# Open Data Laws

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- **Executive Order 13642 (2013):** Making Open and Machine Readable the New Default for Government Information
- **OMB Open Data Policy:**
  - Requires agencies to collect or create information that supports downstream information processing and dissemination
  - Machine readable and open formats
  - Modernizing information systems to maximize interoperability and information accessibility

# Open Data Laws

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## Enforcement

“This order is not intended to, and does not, create any right or benefit, substantive or procedural, enforceable at law or in equity by any party against the United States, its departments, agencies, or entities, its officers, employees, or agents, or any other person.”

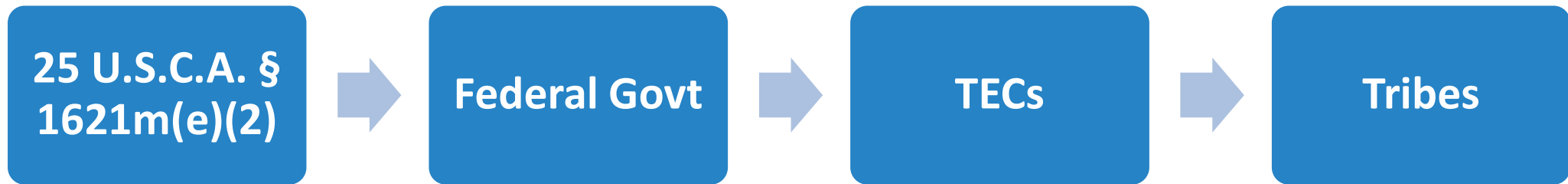
LOL

# Tribal-Specific Requirements

agencies  
specific

# TEC Access

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# Treaty and Statutory Obligations

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- Treaties between the federal government and numerous Tribes obligated the United States to provide health care and other services to Tribes and American Indians in exchange for ceded territory.
- The Snyder Act, Indian Health Care Improvement Act and other laws and legally binding documents reaffirm these obligations.

US Constitution says these are the Supreme law of the land

# HIPAA & Public Health Authorities

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- HIPAA requires “covered entities” (such as hospitals, clinical laboratories, nursing homes, physicians, and health plans) to protect “protected health information” (PHI)
- HIPAA allows for the “covered entities” to provide PHI to “public health authorities” such as state, local, **Tribal agencies** and TECs for certain public health purposes

\* Permissive

# Tribal Law and Order Act (2010)

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- Expanded criminal punitive capabilities of Tribal courts per criminal proceeding
  - 1 year to 3 years or up to 9 years
  - Up to 15k fines
- Requires counsel for indigent defendants
- Law training and licensing for Tribes
- Provides BIA and Tribal police officers with greater access to criminal information sharing databases

# Savanna's Act (2020)

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- Improve federal programming to address Missing and Murdered Indigenous Persons
- Seeks to increase coordination among Federal, State, Tribal, and local law enforcement agencies
- Department of Justice reporting will include available statistics related to missing indigenous persons and murdered indigenous persons
- Federal Tribal, State, and local law enforcement agencies to submit to information pertaining to MMIP collected by Tribal, State, and local law enforcement using the National Crime Information Center (NCIC) and the National Incident Based Reporting System (NIBRS)
- Federal grants for the purposes of reporting

# EO 13175 Tribal Waivers

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## Sec. 6. Increasing Flexibility for Indian Tribal Waivers.

(a) Agencies shall review the processes under which Indian tribes apply for waivers of statutory and regulatory requirements and take appropriate steps to streamline those processes.

(b) Each agency shall, to the extent practicable and permitted by law, consider any application by an Indian tribe for a waiver of statutory or regulatory requirements in connection with any program administered by the agency with a general view toward increasing opportunities for utilizing flexible policy approaches at the Indian tribal level in cases in which the proposed waiver is consistent with the applicable Federal policy objectives and is otherwise appropriate.

(c) Each agency shall, to the extent practicable and permitted by law, render a decision upon a complete application for a waiver within 120 days of receipt of such application by the agency, or as otherwise provided by law or regulation. If the application for waiver is not granted, the agency shall provide the applicant with timely written notice of the decision and the reasons therefor.

# Trust Responsibility

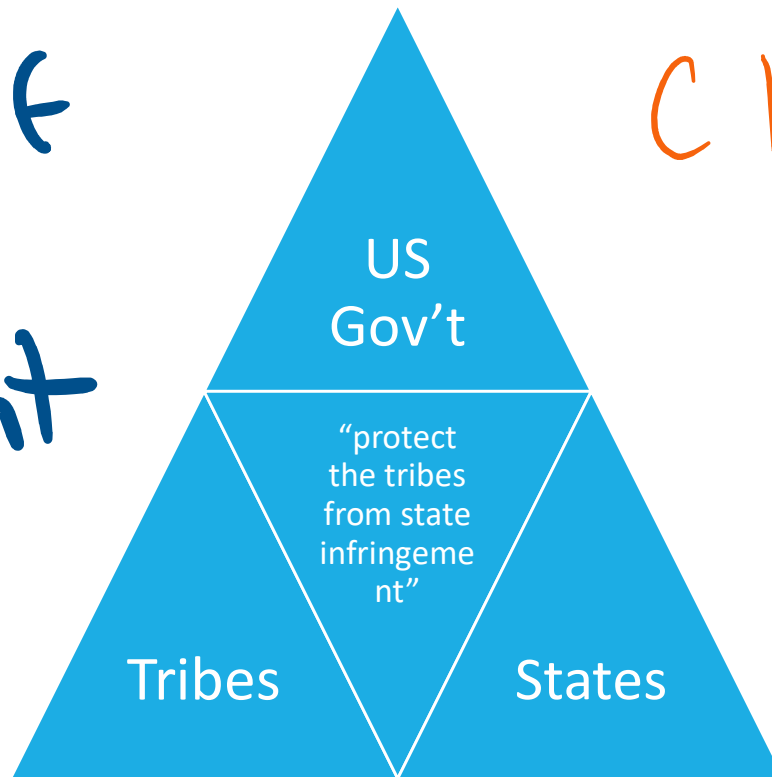
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# Trust Relationship

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Principle of  
Domestic  
Dependent  
Nations



Cherokee Nation v.  
GA  
(1831)

# Trust Relationship

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- The US Supreme Court has found that a unique trust relationship exists between the federal government and the tribes in light of their history, treaties, agreements, legislation, and case law
- Examples
  - Trust lands
  - Trust funds
  - Tribal consultation

*See, e.g., United States v. Mitchell*, 445 U.S. 535 (1980); *Menominee v. United States*, 391 U.S. 404 (1968); *Seminole Nation v. United States*, 316 U.S. 286 (1942); *Cherokee Nation v. Georgia*, 30 U.S. 1, 2 (1831).  
*Passamaquoddy v. Morton*, 528 F.2d 370 (1st Cir. 1975).

U.S. DEPARTMENT OF THE INTERIOR, BUREAU OF INDIAN AFFAIRS, WHAT IS THE FEDERAL INDIAN TRUST RESPONSIBILITY,  
[www.bia.gov/FAQs/index.htm](http://www.bia.gov/FAQs/index.htm).

# Trust Relationship

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“In carrying out its treaty obligations with the Indian tribes the Government is something more than a mere contracting party. Under a humane and self imposed policy which has found expression in many acts of Congress and numerous decisions of this Court, **it has charged itself with moral obligations of the highest responsibility and trust.**”

*Seminole Nation v. United States*, 316 U.S. 286, 296–7 (1942)

# Trust Relationship

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“The federal Indian trust responsibility is also a legally enforceable fiduciary obligation on the part of the United States to protect tribal treaty rights, lands, assets, and resources, as well as **a duty to carry out the mandates of federal law with respect to American Indian and Alaska Native tribes and villages**. In several cases discussing the trust responsibility, the Supreme Court has used language suggesting that it entails legal duties, moral obligations, and the fulfillment of understandings and expectations that have arisen over the entire course of the relationship between the United States and the federally recognized tribes.”

Bureau of Indian Affairs



# Trust Relationship

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“[t]he United States has mismanaged Indian trusts for nearly as long as it has been trustee.”

*Cobell v. Norton (“Cobell VI”), 240 F.3d 1081, 1086 (D.C. Cir. 2001)*

# Breach of Trust Claim

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for monetary damages

## **A breach of Trust Claims thus now requires**

- 1) Express Statutory language supporting a fiduciary relationship
  - This can be a promise of “trust” (*White Mountain Apache*)
  - Establishment of a fiduciary relationship (trustee, beneficiary, and corpus) (*Mitchell II*)
- 2) Comprehensive control and supervision

## Rosebud Sioux Tribe v. US (D.S.D. Mar 31, 2017)

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- Federal surveyors inspected the Rosebud IHS Hospital in mid-Nov of 2015, the Centers for Medicare and Medicaid Services (CMS) sent the Rosebud IHS Hospital a “Notice of Intent to Terminate Medicare Provider Agreement” concerning its emergency department.
- The CMS stated that the deficiencies discovered during the review process were an “immediate and serious threat to the health and safety [of] any individual who comes to [the Rosebud IHS Hospital] to receive emergency services.”
- IHS failed to correct deficiencies despite several notices of noncompliance.

## Rosebud Sioux Tribe v. US (D.S.D. Mar 31, 2017)

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- On March 1, 2016, CMS again sent Rosebud IHS Hospital a termination notice, stating that its Medicare Provider Agreement would be terminated March 16, 2016.
- Hospital closed.
- CMS and IHS entered into a Systems Improvement Agreement to promote future compliance with the Medicare conditions of participation. IHS awarded a contract to AB Staffing Solutions, LLC on May 17, 2016,
- Hospital reopened on July 15, 2016



# Rosebud Sioux Tribe v. US

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- **Count I:** Violation of IHCA (25 U.S.C. § 1631(b)(1)): requires a one-year notice to Congress before any IHS hospital, facility, or portion of such can be closed, in order to evaluate the impact of the closure
- **Count II:** Violation of APA for violation of IHCA
- **Count III:** Violation of treaty rights, other statutory obligations, and the trust responsibility obligating the Government to provide health care services to the Tribe's members
- **Count IV:** Violations of equal protection and due process under the Fifth Amendment of the United States Constitution stemming from the Rosebud IHS Hospital's emergency department closure
- Requests declaratory and injunctive relief, as well as costs, fees, and other relief deemed proper.

Motion to Dismiss  
granted

## Rosebud Sioux Tribe v. US

---

- ✓ **Count I:** Violation of IHCA (25 U.S.C. § 1631(b)(1)): requires a one-year notice to Congress before any IHS hospital, facility, or portion of such can be closed, in order to evaluate the impact of the closure
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- Requests declaratory and injunctive relief, as well as costs, fees, and other relief deemed proper.

# Rosebud Sioux Tribe v. US

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- **Count I:** Now that the Rosebud IHS Hospital emergency department has reopened, the Tribe is not entitled to a declaratory judgment
- **Count II:** same reasoning as Count I
- **Count III:** The above affirmations of a health care trust responsibility are tempered by Supreme Court rulings on the subject of the general trust responsibility, as noted above, and specifically on American Indian health care. The Government argues that because of the lack of a trust corpus, “the sole question is whether the IHS owes any trust duty in relation to its annual appropriations.”
- **Count IV:** allocation of funding must overcome a “strong presumption of constitutionality,” subject to rational basis review

# Rosebud Sioux Tribe v. US

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- Appeal to 8<sup>th</sup> Circuit, decided August 2021
- “In this appeal, we are asked to consider whether the district court erred by declaring the United States has a duty to provide “competent physician-led healthcare” to the Rosebud Sioux Tribe (“the Tribe”) and its members. **In light of promises made to the Tribe more than 150 years ago, and relevant legislation since that time, we find the district court correctly articulated the existence and scope of the duty and declaratory judgment was proper. We affirm.**”

Enforcement

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# Lincoln v. Vigil (1993)

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UNANIMOUS DECISION FOR LINCOLN, ACTING DIRECTOR, INDIAN HEALTH SERVICE, ET AL.

MAJORITY OPINION BY DAVID H. SOUTER

*White*

*Stevens*

*Scalia*

*Souter*



*Rehnquist*

*Blackmun*


*O'Connor*

*Kennedy*

*Thomas*

# Enforcement

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- Demand Letters
  - Requests for Consultation
  - FOIA Claims
  - Breach of Trust Claim
  - Equal Protection Clause/Rational Basis Review (gov't wins)
  - Court of Public Opinion
- 

# Thank you!

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Aila Hoss, JD  
ailahoss@iu.edu





# CURRENT ISSUES IN FEDERAL DATA SHARING

Meghan Curry O'Connell, MD, MPH  
Chief Public Health Officer  
Great Plains Tribal Leaders Health Board  
September 26, 2023







Public Health  $\neq$  “Research”



# Why does this matter?

**Tribes and TECs have a united goal:** To improve the health and well-being of American Indian and Alaska Native persons.

To achieve this, access to timely and representative data is ESSENTIAL.

No problem, right?



# GAO Highlights

Highlights of [GAO-22-104698](#), a report to congressional addressees

## Why GAO Did This Study

AI/ANs have experienced long-standing problems accessing health care services and worse health outcomes than the general U.S. population, such as a life expectancy that is 5.5 years shorter than the U.S. average, according to IHS. To provide tribes with public health support, Congress required the establishment of TECs and, in 2010, authorized their access to HHS data. The COVID-19 pandemic highlighted the need to understand TECs' access to epidemiological data to help AI/AN communities prevent and control diseases.

The CARES Act includes a provision for GAO to report on its ongoing COVID-19 monitoring and oversight efforts. Also, GAO was asked to examine TECs' access to epidemiological data. This report (1) describes TECs' access to and use of epidemiological data, and (2) examines factors that have affected TECs' access to HHS epidemiological data. GAO reviewed HHS policies and documents and documentation of TECs' data requests. GAO also interviewed officials from CDC, IHS,

March 2022

## TRIBAL EPIDEMIOLOGY CENTERS

### HHS Actions Needed To Enhance Data Access

#### What GAO Found

Among the 12 tribal epidemiology centers (TEC), which are public health entities serving American Indian and Alaska Native (AI/AN) communities across the U.S., access to epidemiological data varied. Federal law authorizes TECs' access to data from the Department of Health and Human Services (HHS), including data from HHS's Centers for Disease Control and Prevention (CDC) and Indian Health Service (IHS), for a variety of public health purposes. However, according to TEC officials, access to non-public HHS data, such as CDC data on positive COVID-19 tests or IHS data on patient diagnosis codes, varied among TECs. TEC officials also described challenges accessing some CDC and IHS data, such as the inability to access certain CDC data on infectious diseases and other conditions. TECs used available epidemiological data to monitor the spread of COVID-19 and to conduct other analyses that support public health decision-making in AI/AN communities. However, TEC officials told GAO that their access to data influences the analyses they are able to conduct, and that a lack of access can limit their ability to provide AI/AN communities with meaningful information needed for decision-making.

The presence of CDC and IHS data sharing systems and agreements between the agencies and TECs have facilitated TECs' access to a range of epidemiological data, including on COVID-19 cases and the health of IHS facility patients. However, a number of factors have also hindered TEC access to HHS data, including

- **A lack of policies affirming TECs' authority to access HHS data.** Officials from seven of 12 TECs indicated that some CDC and IHS officials with whom they interacted when requesting data did not recognize that HHS is required by federal law to provide data in its possession to TECs. According to IHS and CDC officials, as of November 2021, HHS had not clarified the specific data that TECs are entitled to access under federal law.





# What data?

“...data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.”

25 USC § 1621m



# Sample HHS Operating Divisions



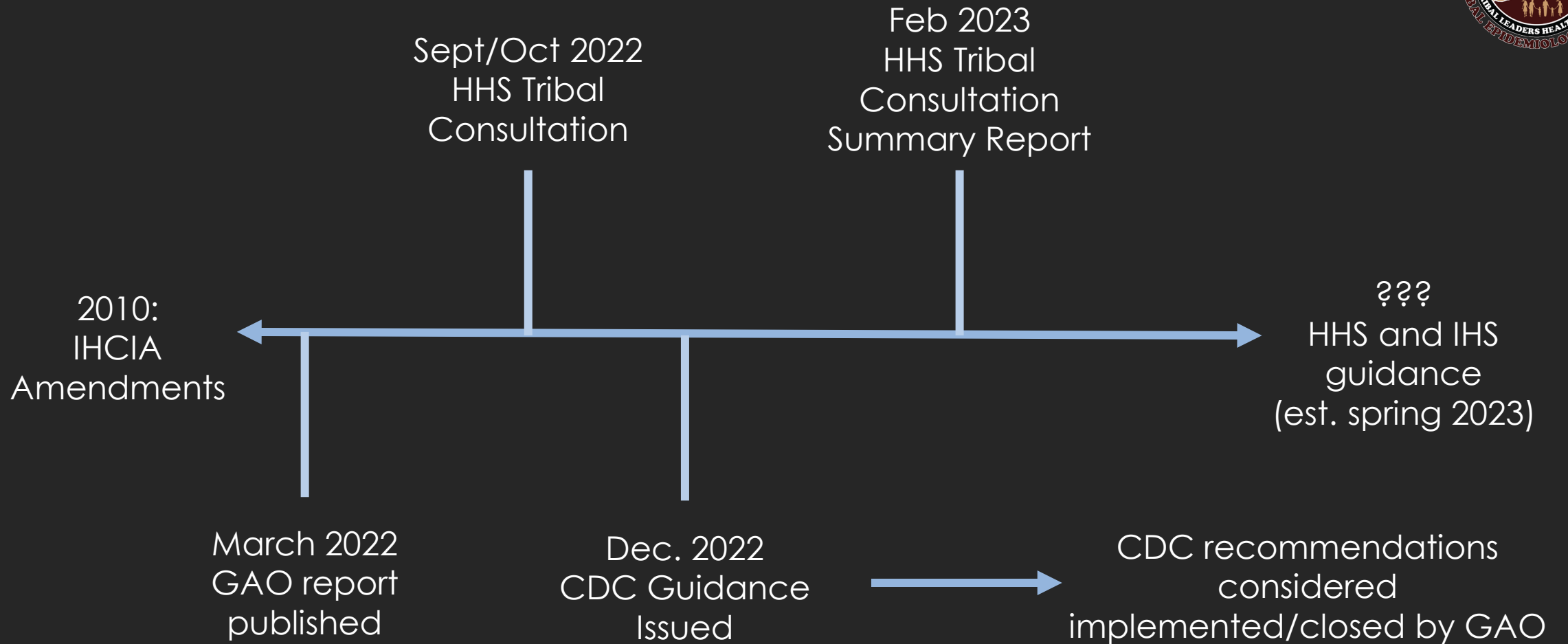
Direct care provider



Health insurance



Public health agency



# Tribal consultation: HHS Tribal Data Sharing Policy



1. What kinds of data-related support from HHS agencies do tribes need?
2. What technical assistance do tribes need to best support their data access and data quality needs?
3. How have barriers to data access affected your efforts to address public health challenges?
4. What are some examples of the type of support that a TEC provides to your public health activities?
5. To what extent should HHS share tribal members' health information with TECs to facilitate their public health activities?
6. What legal/policy barriers have you encountered at the state or local level for accessing data held by those jurisdictions?
7. If tribal affiliation is included in data collection, what are your recommendations for collecting and sharing that type of information?
8. How can HHS agencies improve the quality and utility of AI/AN health data?





# Tribal consultation summary themes

Tribal Sovereignty and Data Sovereignty

Implement Existing Law

Parity of Access without Additional Burdens or Conditions

Flexible and Broad Coverage

Consultation

# CDC Response



## CDC Public Health Datasets and Access Guide for Tribes and Tribal Epidemiology Centers December 30, 2022

| Data Subject               | Lead CDC Center, Institute, or Office                                  | Data System or Dataset  | How To Access the Data  |
|----------------------------|--|---|---|
| Cross-Cutting Data Library | Centers for Disease Control and Prevention (CDC)                       | <a href="#">CDC Data and Statistics</a><br>Cross-agency view of CDC data and statistics and tools for working with the data.  | <ul style="list-style-type: none"> <li>Access <a href="#">CDC Data and Statistics</a> to identify data of interest, points of contact, and information on how to access the data.</li> </ul>  |
| Cross-Cutting Data Library | Center for Surveillance, Epidemiology, and Laboratory Services (CSELS) | <a href="#">CDC WONDER (Wide-ranging ONline Data for Epidemiologic Research)</a><br>Menu-driven system that makes a wide array of CDC's information resources available to public health professionals and the public.  | <ul style="list-style-type: none"> <li>Access the <a href="#">CDC WONDER site</a> to identify data of interest and information on accessing or requesting specific data.</li> </ul>   |
| Health, United States      | National Center for Health Statistics (NCHS)                           | <a href="#">Health, United States</a><br>Presents an overview of national health trends organized around four subject areas: health status and determinants, utilization of health resources, healthcare resources, and healthcare expenditures and payers. Uses data from a wide variety of sources, even external to CDC. Tables examine long terms trends in health over a wide range of demographic and socioeconomic indicators. Estimates for the American Indian/Alaska Native population are presented where available. | <ul style="list-style-type: none"> <li>Access the <a href="#">Health, United States – Data Finder site</a> for current and recent reports. Drop-down menus allow users to search for tables that have data on specific groups.</li> <li>Access <a href="#">Previous Reports</a>.</li> </ul> |
| Healthy People             | National Center for Health Statistics (NCHS)                           | <a href="#">Healthy People</a><br>Identifies public health priorities to help individuals, organizations, and communities across the United States improve health and well-being. Healthy People 2030, the initiative's fifth iteration, builds on knowledge gained over the first four decades. NCHS leads measurement of the nation's   | Access publicly available data: <ul style="list-style-type: none"> <li><a href="#">Healthy People 2030 Objectives</a></li> <li><a href="#">Healthy People 2020 Disparities Data</a></li> <li><a href="#">Healthy People 2020 Progress by Population Group</a> – Choose "Race and</li> </ul> |



## Tribal Public Health Data Request Form

[Print](#)

Information about CDC's relevant data sets is available at [Tribal Public Health Data](#). If you cannot find your answer there, please contact CDC's Office of Tribal Affairs and Strategic Alliances (OTASA) by using the form below. OTASA will provide an answer or triage your request to the relevant CDC program for response.

This service is for tribal nations, Tribal Epidemiology Centers, and Urban Indian Health Centers. Others may request information from [CDC-INFO](#).

Email \*

Please enter your email address.

First Name \*

Last Name \*

Phone \*

Affiliation (i.e., name of tribe, Tribal Epidemiology Center, or Urban Indian Health Center) \*

Data Request/Question \*

protected by reCAPTCHA



[Privacy](#) [Terms](#)

Submit

\* Required field



# Next Steps?

- IHS policy expected by April 2023  
(Not released yet)
- Draft of HHS tribal data sharing policy by late winter 2023
- Final policy by late spring 2023? (2024?)



There's no health equity without  
data equity.

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**...so that the  
people may live**

[Meghan.OConnell@gptchb.org](mailto:Meghan.OConnell@gptchb.org)

605-510-7786(c)



# Lessons from COVID-19: How Partnerships and GIS Can Facilitate Data Sharing and Improve Health Equity

September 25, 2023

Amanda Lam, MD, MPH & Tyler Baccam, MS

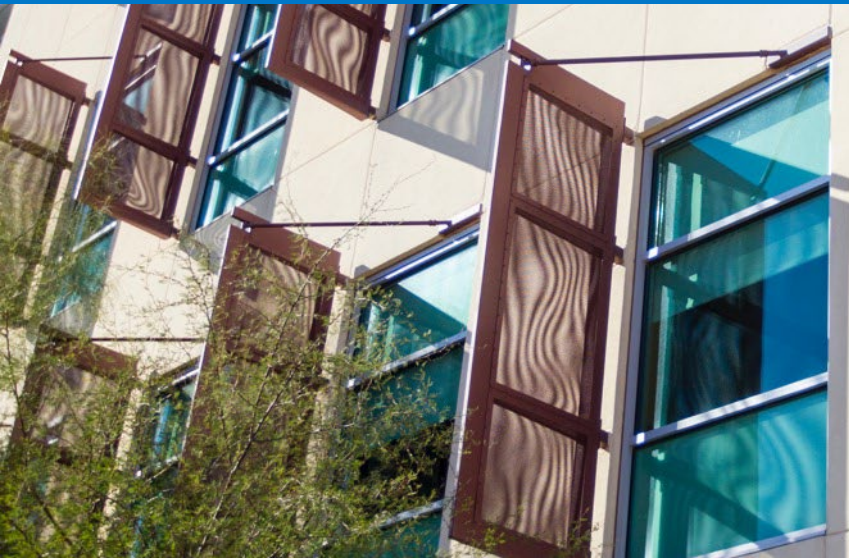
National Indian Health Board Equity Data  
Symposium

# Land acknowledgment

On behalf of Pima County residents, we honor the tribal nations who have served as caretakers of this land from time immemorial and respectfully acknowledge their homelands and presence within Pima County. Consistent with Pima County's commitment to diversity and inclusion, we strive toward building equal-partner relationships with Arizona's tribal nations.

# Outline

- Background – AZ Surveillance & Tribal Collaboration
- Methods – Using GIS to Identify Tribal Data
- Results
- Discussion
- Future Developments





# Background

## *Pima County, Arizona*

- South-central region of the State of Arizona
- Population size: 1.1 Million
- Migratory population
- Diversity
  - 51% White, 38% Latinx, 4% Black, 4% Indigenous, and 3% Asian, 0.2% Pacific Islander



# Background

## *Arizona Surveillance Data*

- The Medical Electronic Disease Surveillance System (MEDSIS)
  - Secure web-based, centralized, person-based disease surveillance system for Arizona Dept of Health Services (ADHS)
  - Reportable diseases and epidemiological investigation data
- State assigns jurisdiction: counties, territories, and tribes
  - Only the state and jurisdiction can view their specific jurisdiction health data
  - Jurisdiction mostly identified through location of case home address or location of health care provider



# Background

## *Difficulties of Tribal Health Data*

- Tribal Specific Data
  - Case gets assigned to Tribal Jurisdiction
  - Other available variables are Tribal Affiliation and Race
- Difficulties tribes have for completeness of health data:
  - Tribal members go to non-IHS or non-Tribe-associated provider
    - > Provider may not be able to correctly identify as tribal member or from community
    - > Case may not state they are associated with a tribe
  - Case investigation can misclassify case
- Jurisdiction typically defaults to the County



# Tribal Collaboration

## *Tribe Requests Data*

- Problem: **Underreporting of tribal health data due to misclassification of tribal jurisdiction. Tribal health data is incomplete and not fully representative (MEDSIS)**
- Tribe requested to have a more complete database for public health data
- County is default jurisdiction of health data based on location



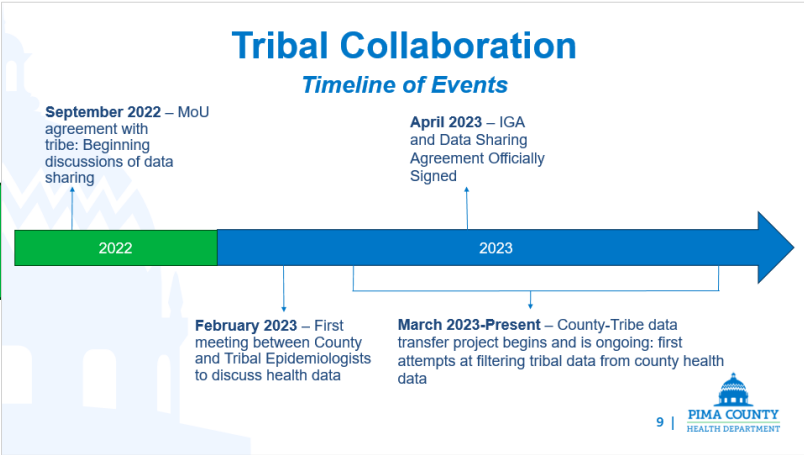
# Tribal Collaboration

## Timeline of Events

**Early 2020** – COVID-19 pandemic creates contact tracing and case investigation data. Case investigations mostly handled by state and large counties.



**2020-2022** – Tribe requests better access to COVID-19 data. Discussions between Tribe and County data sharing centered around COVID-19. Tribal and County health departments grow in capacity



# Tribal Collaboration

## *Timeline of Events*

**September 2022** – MoU agreement with tribe: Beginning discussions of data sharing

**April 2023** – IGA and Data Sharing Agreement Officially Signed



**February 2023** – First meeting between County and Tribal Epidemiologists to discuss health data

**March 2023-Present** – County-Tribe data transfer project begins and is ongoing: first attempts at filtering tribal data from county health data

# Tribal Collaboration

## *Plan for County and Tribe Data Transfer*



County requests MEDSIS data from ADHS



County identifies tribal health data incorrectly assigned to county jurisdiction

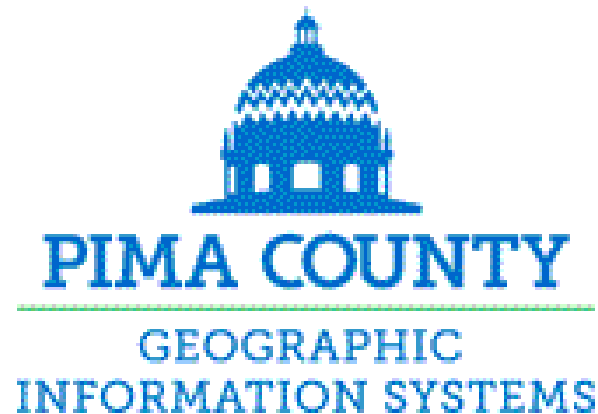


Securely transfer tribal health data through spreadsheets and MEDSIS system

# Tribal Collaboration

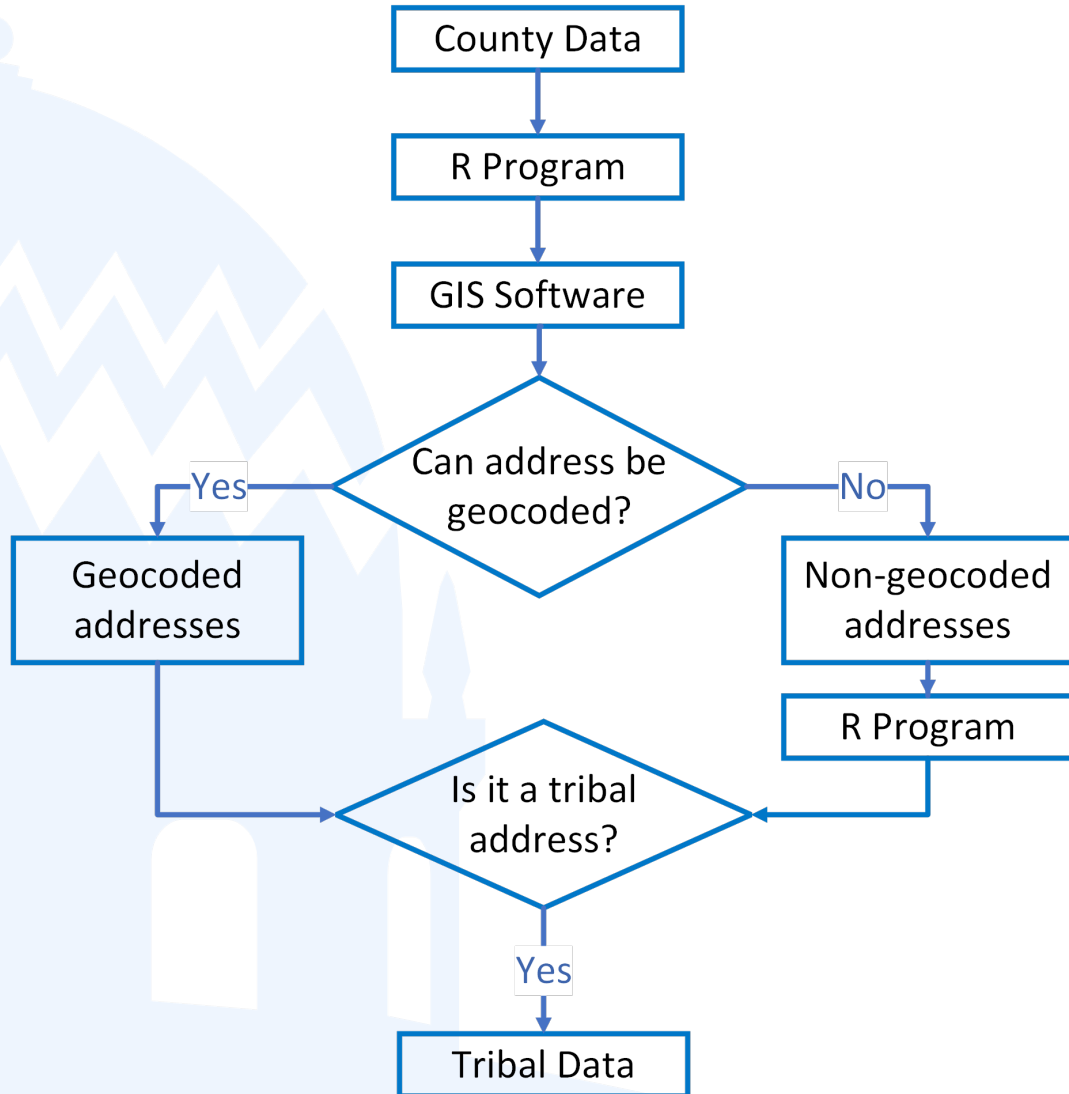
## *Geocoding as a Solution*

- Filtering on Tribal Affiliation alone was not going to catch all tribal health data
  - Self-reported variable
  - Not always asked by provider or case investigator
- Use of geocoding to identify tribal health data based on patient address





# Methodology



- R Program:

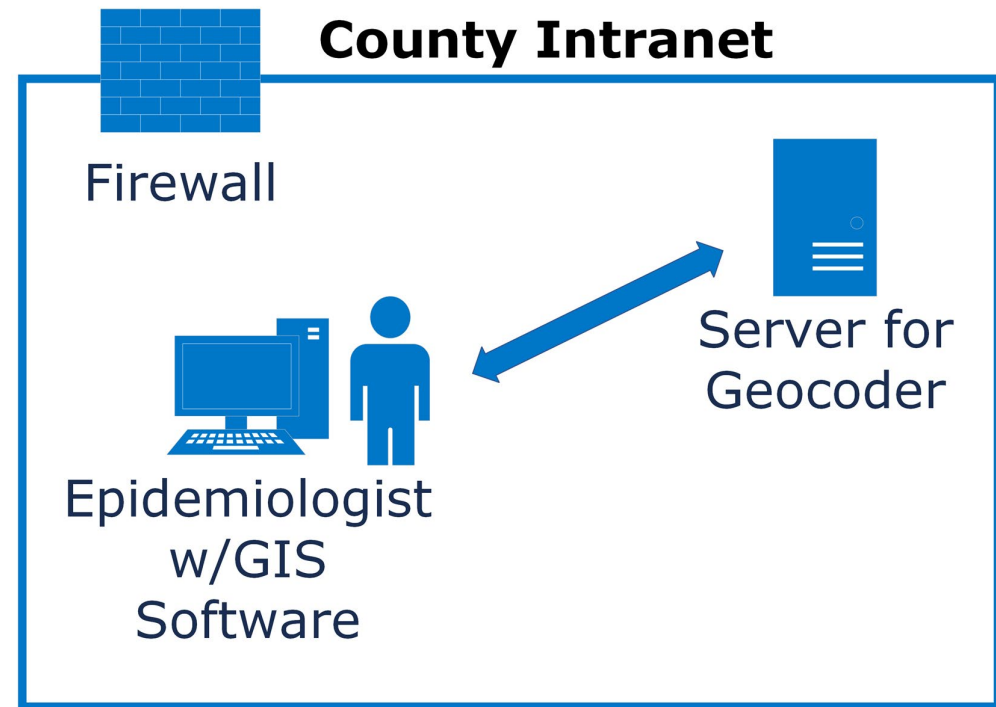
- Pre-geocoding: Address standardization and correction
- Post-geocoding: Identify likely tribal addresses for manual review
  - > Also: Off-reservation w/tribal affiliation

- GIS Software:

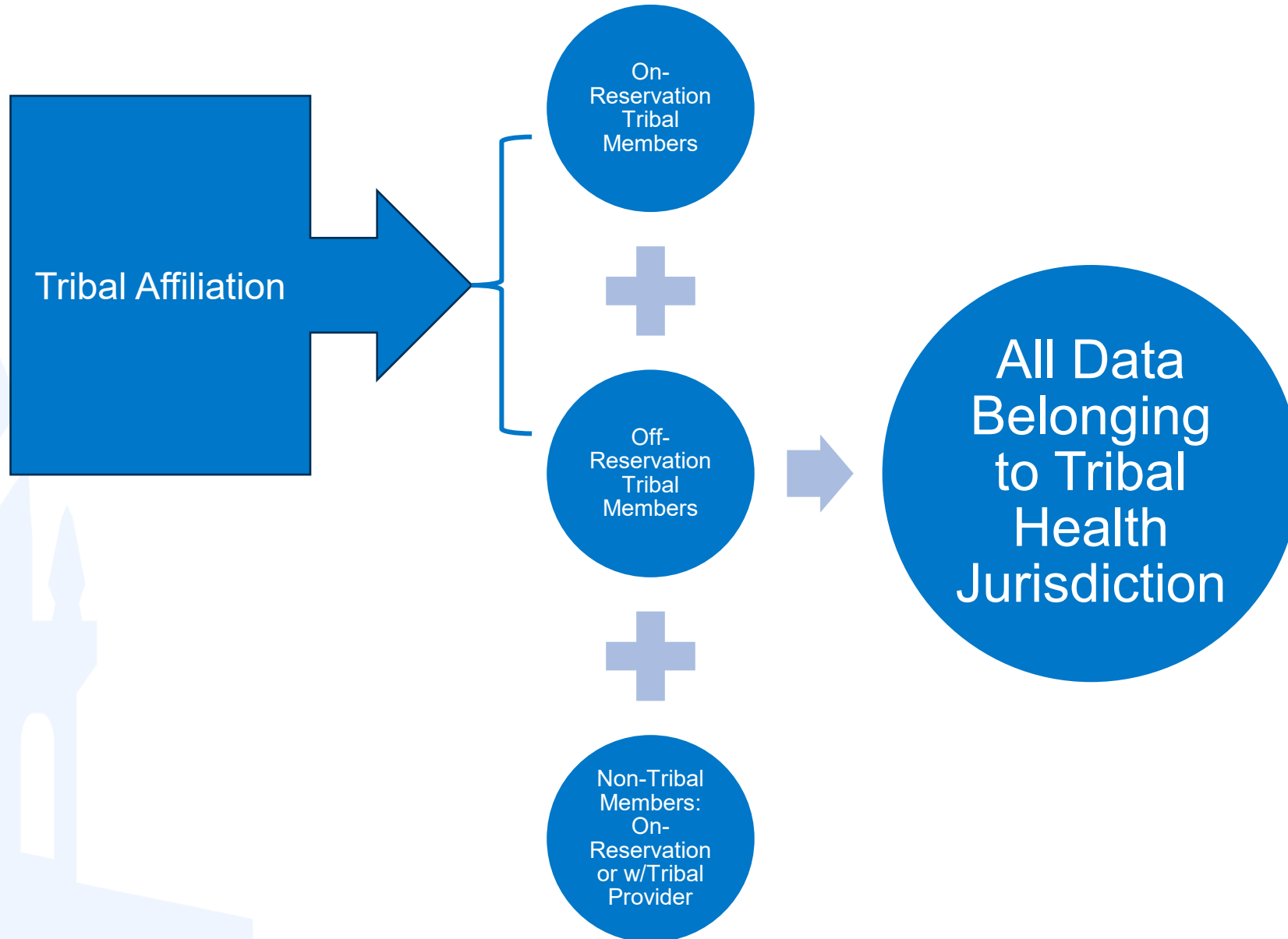
- Spatial join to find matches on tribal land

# Methodology

- Maintain HIPAA compliance by using a local application installation that keeps the geocoding process within the county intranet
- Transfer or share matches via database interface or via secure file sharing link



# Defining Communities



# Results

|  | COVID-19 Case Records<br>(Dec 30, 2019 – Dec 31, 2022) |
|--|--|
| Total # of county records              | 374,653  |
| Total # on-reservation                 | 2,801  |
| With tribal affiliation <sup>(a)</sup> | 1,464 (52.27%)   |
| W/o tribal affiliation <sup>(b)</sup>  | 1,337 (47.74%)   |
| With AI/AN race                        | 1900 (68%)   |
| Total # w/tribal affiliation           | 2,886  |
| On-reservation                         | 1,464 (50.73%)   |
| Off-reservation <sup>(c)</sup>         | 1,422 (49.27%)   |
| With AI/AN race                        | 2,661 (92.20%)   |
| Total # of tribal records identified   | 4,223  |
| With AI/AN race                        | 3,167 (74.99%)   |
| With tribal affiliation                | 2,886 (68.34%)   |

*(a) Only includes records that are labeled with a tribal affiliation. Does not represent actual % of tribally affiliated people who live on-reservation, (b) Or affiliated with other tribe, (c) Includes empty addresses and PO Boxes*

# Results

## *Evaluation of address processing*

|   | COVID-19 Cases<br>(n=374,653) |
|---|-------------------------------|
| Geocoding rate w/o address processing   | 89.66%                        |
| Geocoding rate of subset w/address processing <ul style="list-style-type: none"><li>• Empty address fields and blank street numbers removed</li></ul> | 95% (n=354,406)               |
| # of matches w/o address processing   | 2,629                         |
| # of matches w/address processing   | 2,801                         |
| # of additional matches   | 172 (6.14%)                   |

# Discussion

- The new methodology identified 1.913 times as many COVID-19 case records on the reservation as filtering by tribal affiliation.
- The percentage of matches without the tribal affiliation of interest (48%) represents the “lost” data that the tribe did not have access to about their reservation during the pandemic.

# Limitations

- Any tribal member whose record has neither a reservation address nor the specific tribal affiliation of interest is missed.
  - Without tribal affiliation, cannot identify community members who have off-reservation address, blank address, PO box, or other non-residential address.
  - With tribal affiliation, can miss person who holds more than one tribal identity.
- False or missed matches can occur if the GIS software geocodes an address incorrectly or if an incorrect address is listed in the record, though these errors are mitigated by validation using the mapping software and custom R program.

# Future Developments

- Integrate data tool in disease surveillance and pandemic preparation efforts at tribal, local, and state levels.
- Apply the methodology to COVID-19 vaccinations and non-COVID-19 public health data such as non-COVID-19 infectious disease case records and childhood vaccination records.
- Better understand current workflows and user interfaces to improve data collection of demographics, address, and tribal affiliation.



# Future Developments

- Improvements to the address processing code could use natural language processing to build address standardization and correction models specific to tribal addresses.
- For tribal nations with addresses that are not already part of an existing geocoder, the reference data used by the geocoder can be expanded using GIS software.

# Contact Info

- Amanda Lam – Data and Informatics  
Epidemiologist
  - [Amanda.Lam@pima.gov](mailto:Amanda.Lam@pima.gov)
- Tyler Baccam – Surveillance Epidemiologist
  - [Tyler.Baccam@pima.gov](mailto:Tyler.Baccam@pima.gov)
- Mariana Singletary – Clinical, Border, and Tribal  
Epidemiology Program Manager
  - [Mariana.Singletary@pima.gov](mailto:Mariana.Singletary@pima.gov)



# Putting it into Practice: Story as Data and Data as Story

**Dawn Hunter, JD, MPH – Director, Health Equity**

**Presented September 26, 2023**

**National Indian Health Board**

**Tribal Health Equity Data Symposium**

## About Me



Pictures of my grandparents

I am...

- a biracial Black woman
- a sister and an auntie
- a child of Air Force parents
- a former scientist
- a lawyer
- an avid traveler
- a family history researcher

# Why I Became a Lawyer



**John Lewis**   
@repjohnlewis



Without the brave journalists who covered our protests, the civil rights movement would have been like a bird without wings. [#WPF2015](#)

6:01 PM · May 3, 2015

Image: Tweet from Rep. John Lewis

# Storytelling as an Advocacy Tool – The “Why”

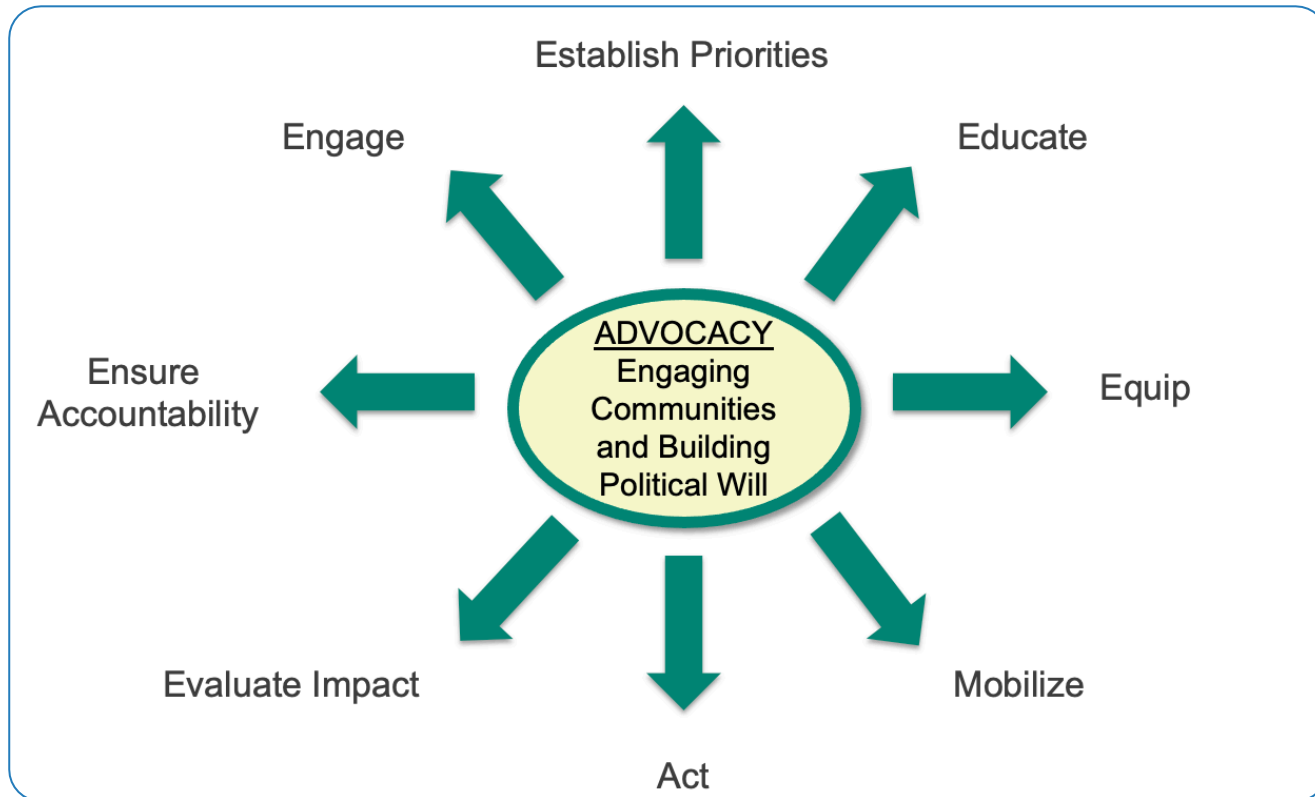
- ✓ **Helps us make sense of the world**
- ✓ **Influences behavior**
- ✓ **Increases knowledge or awareness**
- ✓ **Shapes our values and beliefs**
- ✓ **Teaches us skills**
- ✓ **Builds connection**
- ✓ **Cements things in our memory (especially emotional memory!)**



<https://www.mobilecause.com/storytelling-for-your-organization/>



## The Many Forms of Advocacy

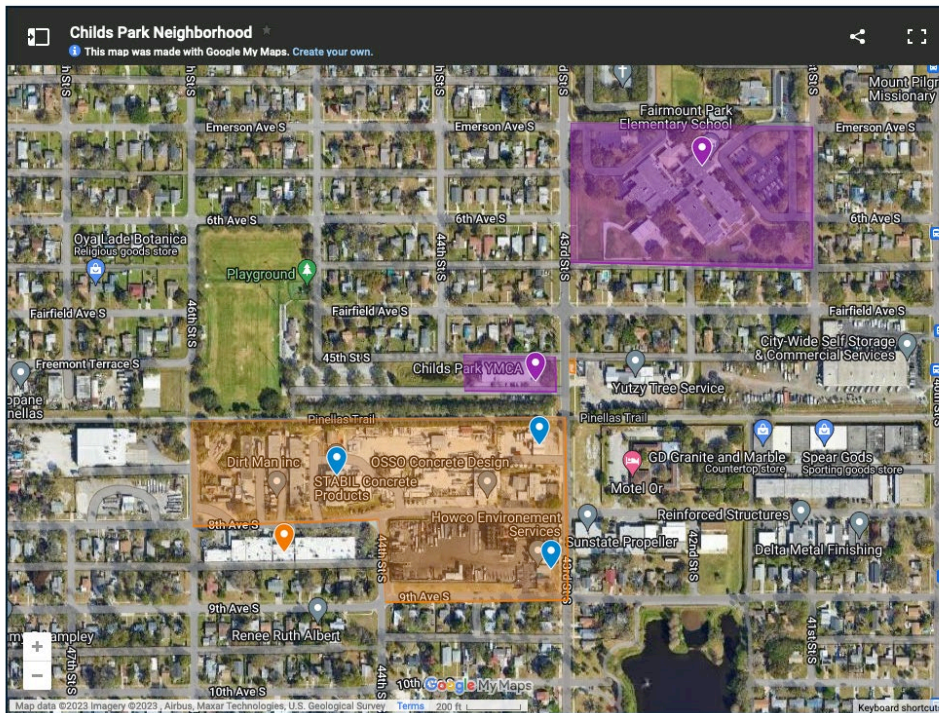


Adapted from the **5 Essential Public Health Law Services**

Burris S, Ashe M, Blanke D, *et al.* Better Health Faster: The 5 Essential Public Health Law Services. *Public Health Reports.* 2016;131(6):747-753.

# Data, Storytelling, and Advocacy – An Example

The *Smell Something, Say Something* Campaign  
Childs Park Neighborhood, St. Petersburg, FL



- **Orange:** Industrial Corridor
- **Purple:** Schools, Recreational Areas, and Parks

Retrieved from: <https://baynews9.com/fl/tampa/news/2023/05/23/what-s-that-smell-that-s-lingered-for-decades-in-st--pete-s-childs-park-neighborhood->



# Data, Storytelling, and Advocacy – An Example

## **Smell Something Say Something** *(Childs Park Neighborhood)*

Thank you for reporting neighborhood odors to the *Smell Something Say Something Campaign*, with your help we received over 60 complaints that were sent to the **County's Air Quality Division** for follow up. The county has updated their **seeclickfix** to make reporting odor issues directly to their office easier. It is important to continue reporting **every time** you smell odors in your neighborhood so that the County knows the issues are still present.

**THIS FORM IS NO LONGER BEING MONITORED.** Please report smells to the County for investigation here:

[https://seeclickfix.com/web\\_portal/Sed47QcE6KStPiNrih3RJLnQ/report/category/41773/location](https://seeclickfix.com/web_portal/Sed47QcE6KStPiNrih3RJLnQ/report/category/41773/location)

---

Survey for Childs Park neighborhood residents to report when and where they smell offensive odors to help gather air quality data and information. Your report will go to neighborhood leaders and the County Air Quality Division for investigation.

# Anamalia Su'esu'e, MA

- Raised in Ka'a'awa and Kea'au, Hawai'i. Family is from the villages of Utulei, Fagatogo, and Fitiuta, American Samoa
- Community Psychology doctoral student at the University of Hawai'i at Mānoa
  - MA, Psychology, May 2023
  - Research interests: culturally responsive policies and programs for Native Hawaiians and Pacific Islanders in health and education
- Graduate research assistant with Dr. Lorinda Riley in the Office of Public Health Studies since September 2021.
- Summer 2023 - Public Health Law Fellow, CDC and ChangeLab Solutions with Dr. Meghan O'Connell at the Great Plains Tribal Leaders' Health Board
  - Tribal health data access policies





# Talk story- Hawai‘i

- What is talk story?
  - informal, relaxed, less about accurate transfer of information and more about connection
  - “affect-rich life stories in a variety of contexts..relate through shared experiences” (Tengan, 2008, p. 164)
- Co-construct understandings and build trust while delving deeper into the questions or topics (Chung-Do et al., 2016)



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# Talanoa

- “Talanoa is natural for most Pacific peoples” (p. 25, Vaioleti, 2006)
- Prioritizes respect, respectful relationships in knowledge sharing
- Open, flexible, collaborative conversation
- “non-linear and responsive approaches” (p. 25, Vaioleti, 2006)



# RESEARCH USING TALK STORY



International Journal of  
Environmental Research  
and Public Health



Article

## Ke ala i ka Mauiola: Native Hawaiian Youth Experiences with Historical Trauma

Lorinda Riley <sup>1,\*</sup>, Anamalia Su'esu'e <sup>2</sup>, Kristina Hulama <sup>3</sup>, Scott Kaua Neumann <sup>4</sup> and Jane Chung-Do <sup>1</sup>

<sup>1</sup> Thompson School of Social Work and Public Health, Office of Public Health Studies, University of Hawai'i Mānoa, Honolulu, HI 96822, USA

<sup>2</sup> Department of Psychology, College of Social Sciences, University of Hawai'i Mānoa, Honolulu, HI 96822, USA

<sup>3</sup> Thompson School of Social Work and Public Health, Social Work, University of Hawai'i Mānoa, Honolulu, HI 96822, USA

<sup>4</sup> Humanities Division, University of Hawai'i West O'ahu, Kapolei, HI 96707, USA

\* Correspondence: lorindar@hawaii.edu

**Abstract:** Native Hawaiians (NH), like other Indigenous peoples, continue to experience the subversive impacts of colonization. The traumatic effects of colonization, especially the forced relocation from land that sustained their life and health, have led to complex, interconnected health disparities seen today. NHs have described a collective feeling of kaumaha (heavy, oppressive sadness) resulting from mass land dispossession, overthrow of the Hawaiian Kingdom, cultural loss, and early loss of loved ones. Although historical trauma is linked to high rates of substance misuse, depression, suicidality, and other mental health disparities in American Indian populations. However, the link between NH historical trauma and health disparities among NHs has been less explored. This qualitative study used **Indigenous talk story interviews** with 34 NH 'ōpio (youth) and ka lawelawe (service providers) to explore how NH 'ōpio understand and experience historical trauma. Eight themes and 35 sub-themes were identified covering individual, community, and systemic domains representing the first step in addressing NH historical trauma.

**Keywords:** indigenous people; historical trauma; wellbeing; Native Hawaiian



Citation: Riley, L.; Su'esu'e, A.; Hulama, K.; Neumann, S.K.; Chung-Do, J. Ke ala i ka Mauiola: Native Hawaiian Youth Experiences with Historical Trauma. *Int. J.*

Category 3 - Investment in Community

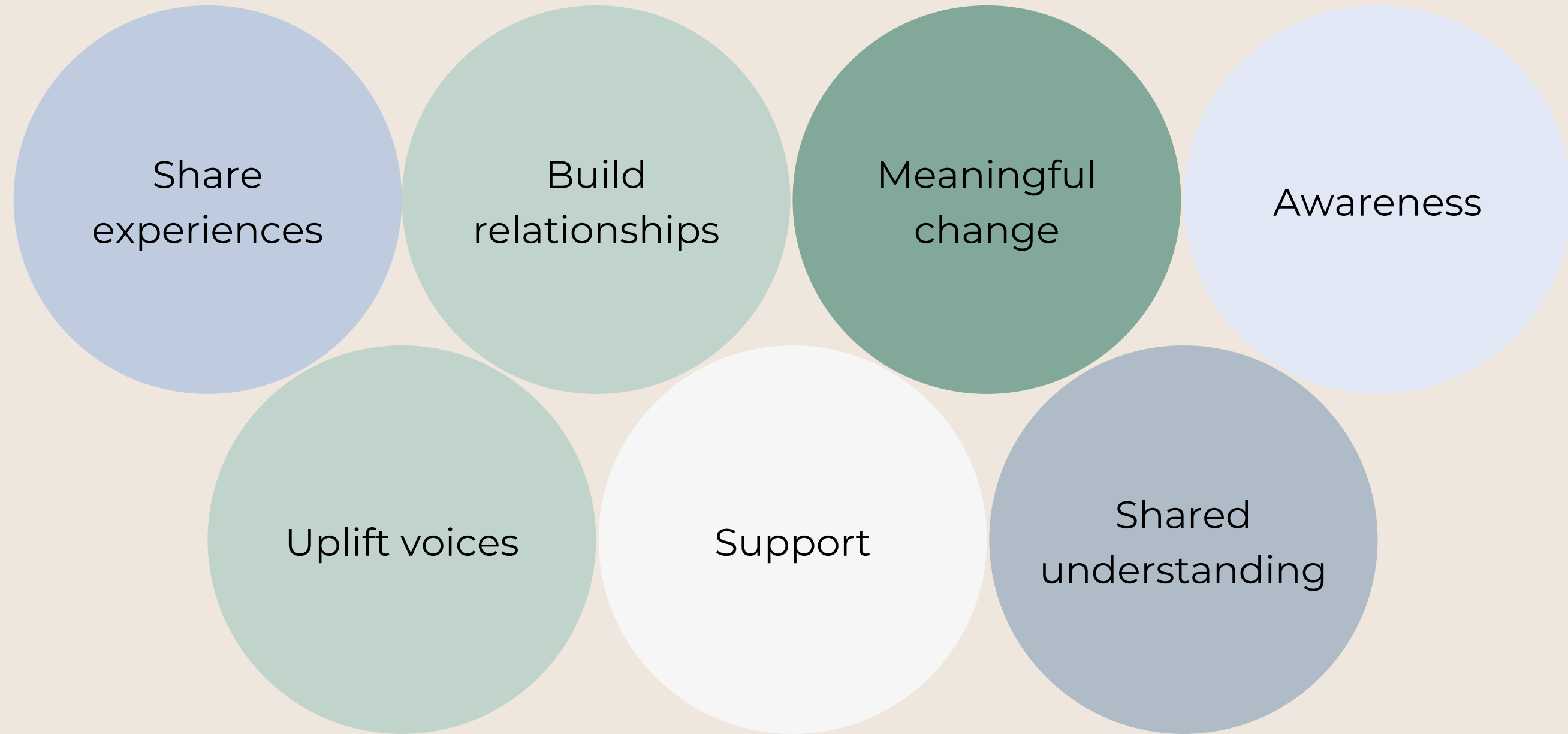
## Theme 6: Reconnecting with Culture

- Participants' desire to learn more about their Samoan culture (i.e., language, history, etc.) and their plans to pursue this learning to make more meaningful connections with their community, especially older and younger generations
- Connections to Hawaiian Studies and learning via social media

Now that I have children, it's important for them to understand where they came from, now that my dad is no longer able to tell stories about our family about where he's from...**if you don't practice storytelling, you are losing a piece of your history...And so I think as my son gets older, I certainly want to be able to know what the heck I'm talking about and be able to pass that on to him.**

**[Hawaiian Studies] was my favorite class because I excelled in that class.** But I think it would have been so fun to have some kind of like, language or culture course just for Samoan. I mean, I know that's hard, because they're so like, multiethnic in Hawai'i. So I guess we would have to do that for everybody. But that would be dope, if we could. **Cultural classes for everybody like that would be amazing.**

# IMPORTANCE OF STORIES



# Small Group Discussions

# Data, Storytelling, and Advocacy for Health Equity

An exploration in small group conversations

1. What is the most important thing you think others should know about health data and your Tribe, and why?
2. What challenges have you experienced using health data to advocate for the health of your Tribe?
3. What makes an equitable Tribal health data ecosystem?
4. What is one action that government entities can take to improve Tribal data access?



# Sharing Your Stories



# Recap



# NIHB Data Projects

Electronic Case Reporting – Tribal Pilot & Roadmap Development

Tribal Maternal Mortality Review Committee Exploratory Project

CMS & IHS Data Match

Medicaid Unwinding

Advocacy for improved data access

OMB SPD 15 – Tribal Consultation

Data Modernization

- IHS
- CDC

# Tribal Advisory Committees



IHS ISAC, NIH, CDC Tribal Advisory Committees have frequent discussion about data



Critical avenue for collaboration and advocacy to ensure policy development and data modernization follows Tribal priorities




Open seats at the table – we want every Area represented!



NIHB provides technical assistance to Tribal leaders serving on federal Tribal advisory committees

# Tribal Advisory Committee Resources



**National Indian Health Board**

Home | Tribal Resources | Legislative | Public Health | Behavioral Health | Communications | For Youth | About NIHB | Donate

### Tribal Advisory Committees

The National Indian Health Board (NIHB) provides support and policy expertise to Tribal Advisory Committees, which are established to enhance the government to government relationship, honor Federal trust responsibilities and obligations to Tribes and American Indian and Alaska Native people, and increase understanding between federally-recognized Tribes and federal agencies.

**Current Tribal Advisory Committee Vacancies as of 9/14/21**  
[\(CLICK TO DOWNLOAD FULL DETAILED LISTING\)](#)



**TRIBAL RESOURCES**

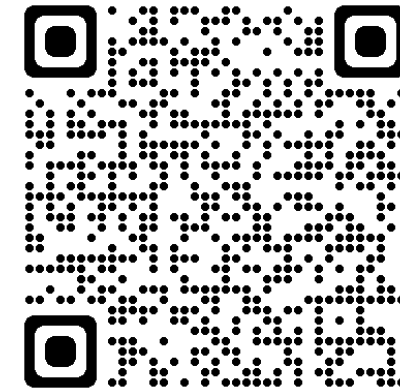
- Agency Links
- Tribal Health Reform Resource Center
- Tribal Advisory Committees**
- Events Calendar
- Funding & Opportunities
- Indian Health 101
- NIHB Newsletters and Publications

**Washington Report**  
An NIHB Publication

The Washington Report is an e-newsletter produced by the National Indian Health Board. Each issue contains a listing of current events on Capitol Hill, information on passed and upcoming legislation, Indian health policy analysis and action

To request Technical Assistance or if you have any questions regarding TAC's, email:

[FederalRelations@nihb.org](mailto:FederalRelations@nihb.org)

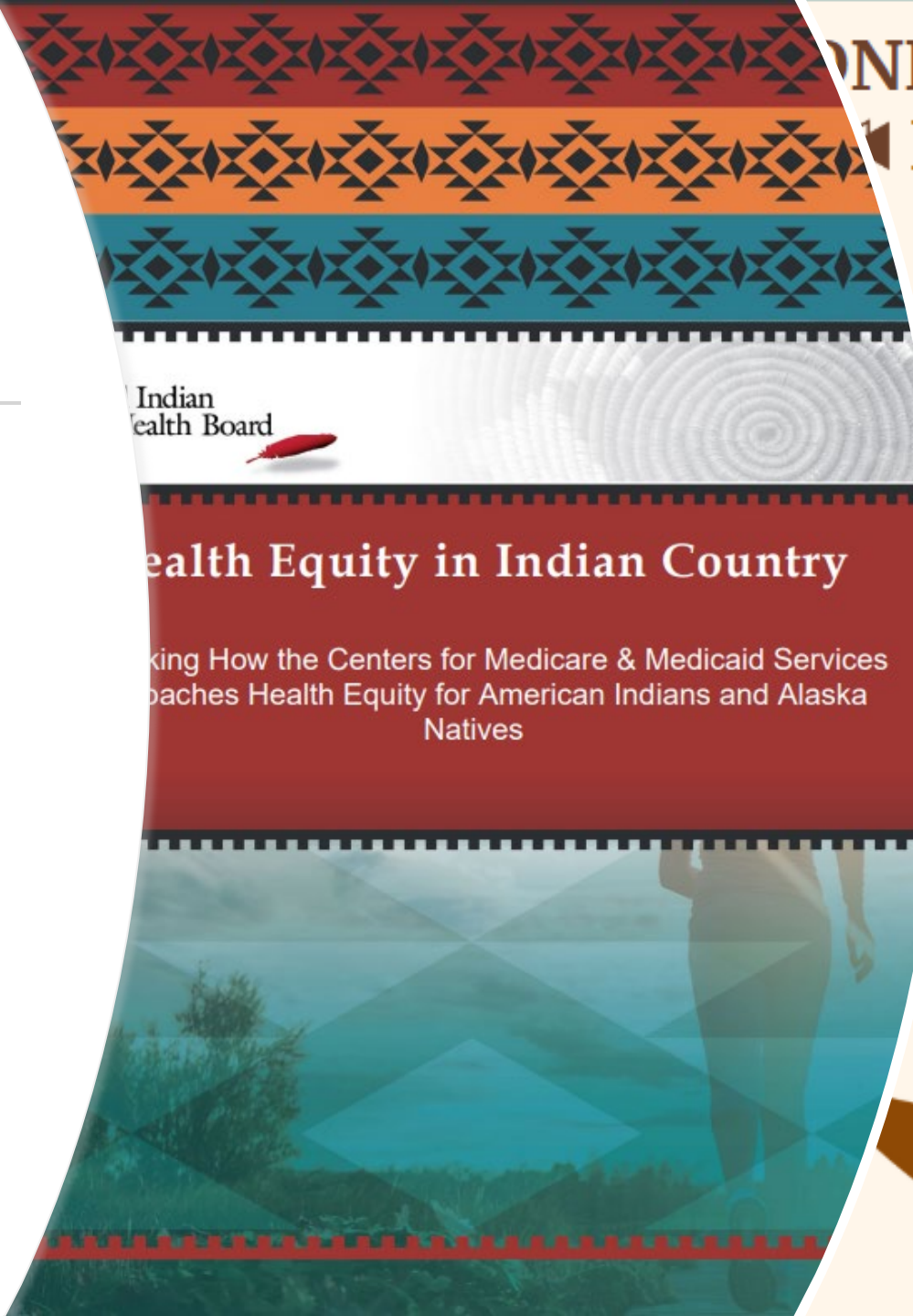
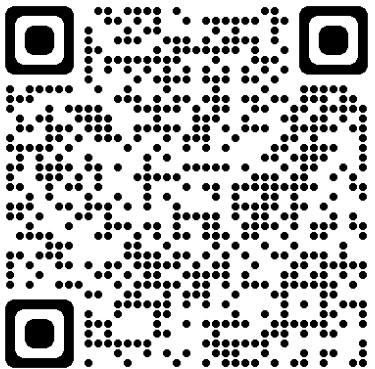


Scan QR Code to visit NIHB's TAC Webpage

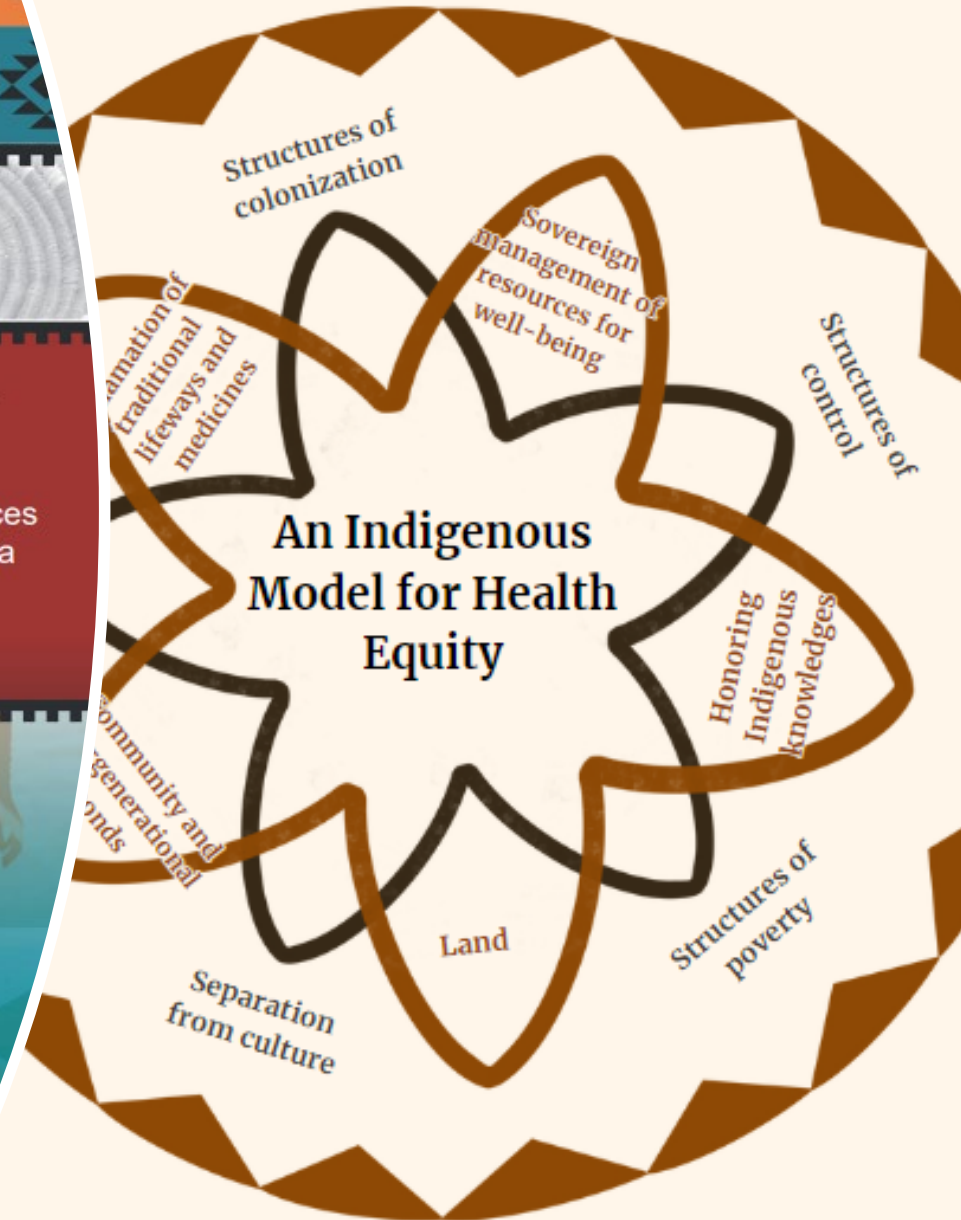


# Tribal Health Equity Resources

[www.nihb.org/  
health-equity](http://www.nihb.org/health-equity)



## ONE IN THE SAME BASKET HEALTH AND EQUITY



# What's next?



Tribal Health Equity Data Symposium Report



“Story as Data” Videos – advocacy opportunity



Request for additional Tribal Consultation on OMB SPD 15 NIHB advocacy for improved data access



Collaboration towards improved data quality, especially in healthcare settings

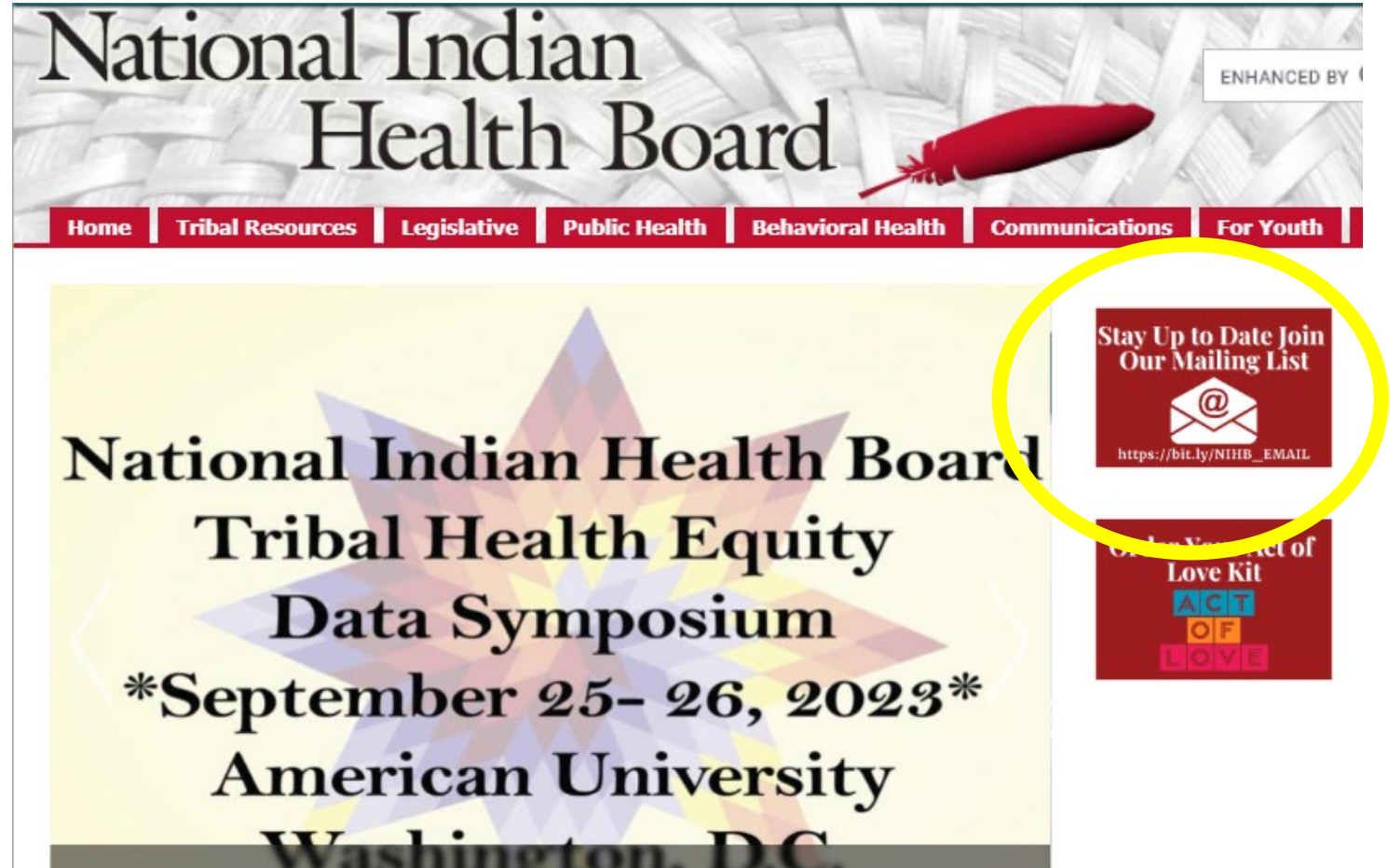


Updates will be shared at [nihb.org/health-equity](https://nihb.org/health-equity)

# Save the Date!

## 2024 National Tribal Health Conference

- **May 2024**
- **Rapid City** - Great Plains Area
- Abstract Proposal Submissions open by November 1
- Continued conversations on data and health equity
- Stay up to date with NIHB social media or join our email list



The image shows a screenshot of the National Indian Health Board website. The header features the text "National Indian Health Board" in a large, serif font, with a red feather graphic to the right. Below the header is a navigation menu with links for "Home", "Tribal Resources", "Legislative", "Public Health", "Behavioral Health", "Communications", and "For Youth". The main content area displays a large, colorful geometric star graphic with the text "National Indian Health Board Tribal Health Equity Data Symposium \*September 25- 26, 2023\* American University Washington, D.C.". On the right side of the page, there is a red button with white text that reads "Stay Up to Date Join Our Mailing List" and a small icon of an envelope with an @ symbol. Below this button is a URL: [https://bit.ly/NIHB\\_EMAIL](https://bit.ly/NIHB_EMAIL). The button and URL are circled in yellow.



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[nihb.org/health-equity](https://nihb.org/health-equity)

# EVALUATIONS



Scan the QR code to the left with your phone camera to take the [evaluation survey](#) online.

