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Barriers and Opportunities for Tribal Access to Public Health Data to Advance Health Equity



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2023

PUBLIC HEALTH LAW
CONFERENCE

People. Policy. Progress.

October 24 – 26, 2023
Renaissance Depot Hotel
Minneapolis, MN

National Indian Health Board



NIHB Mission Statement: Established by the Tribes to advocate as the united voice of federally recognized American Indian and Alaska Native Tribes, NIHB seeks to reinforce Tribal sovereignty, strengthen Tribal health systems, secure resources, and build capacity to achieve the highest level of health and well-being for our People.

How does NIHB pursue this mission?

Advocacy

Policy Formation
and Analysis

Training and
Technical
Assistance

Capacity Building

Programmatic
Support

Direct Funding

Legislative and
Regulatory
Tracking

Direct and Timely
Communication
with Tribes

Research on
Indian Health
Issues

What type of organization do you work for?

(A) State

0%

(B) Local

0%

(C) Tribal or Tribal Serving

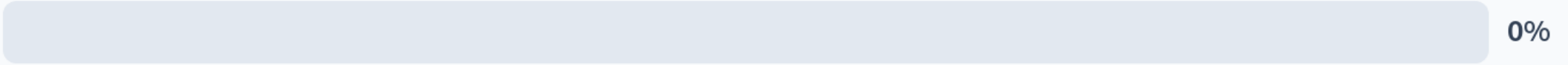
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(D) Other

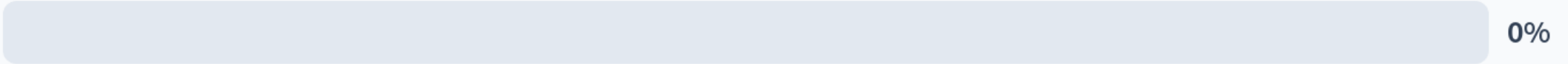
0%

How confident are you in your understanding of Tribal data sovereignty?

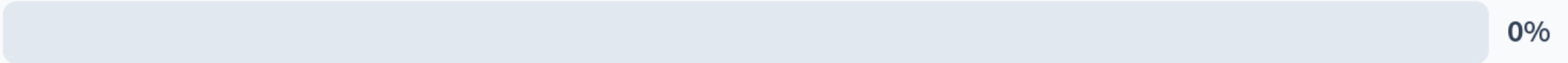
Not Confident



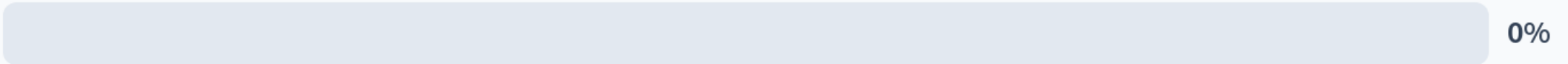
Somewhat Confident



Moderately Confident



Very Confident



Start the presentation to see live content. For screen share software, share the entire screen. Get help at pollev.com/app

How many federally recognized Tribes are there within the United States?

272

0%

512

0%

574

0%

1007

0%

12

0%

Which of the following agencies provide public health services in Indian Country?

Tribes

0%

IHS

0%

State Health Agencies

0%

Local Health Agencies

0%

Tribal Epidemiology Centers

0%

CDC

0%

All of the above

0%

What does Tribal sovereignty mean to you?

Nobody has responded yet.

Hang tight! Responses are coming in.

Learning Objectives

- By the end of the session, participants will be able to:
 - Be able to explain the importance and legal foundations of Tribal data sovereignty
 - Identify next steps for improving public health data sharing with Tribes

Agenda Overview



Introduction to Tribal Public Health



Federal Indian Law 101



Legal Foundations of Public Health Data Sharing in Indian Country



Case Study: Electronic Case Reporting as a Path for Respecting Tribal Sovereignty



Bringing it All Together: Data, Health Equity, and Paths Forward



Discussion

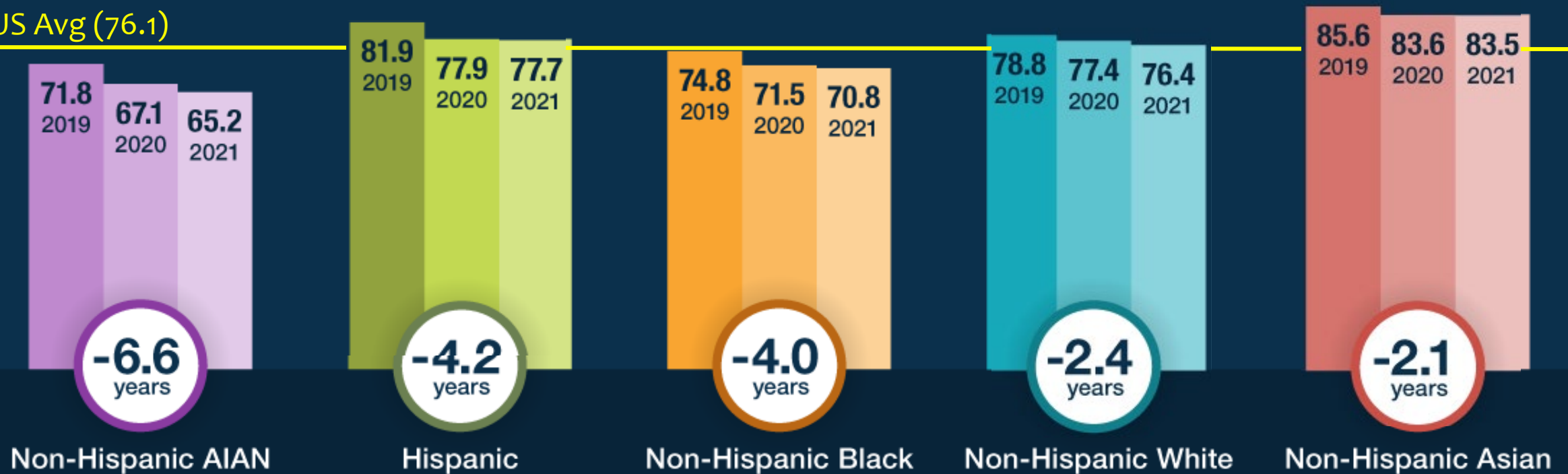
Here's the Main Takeaway:

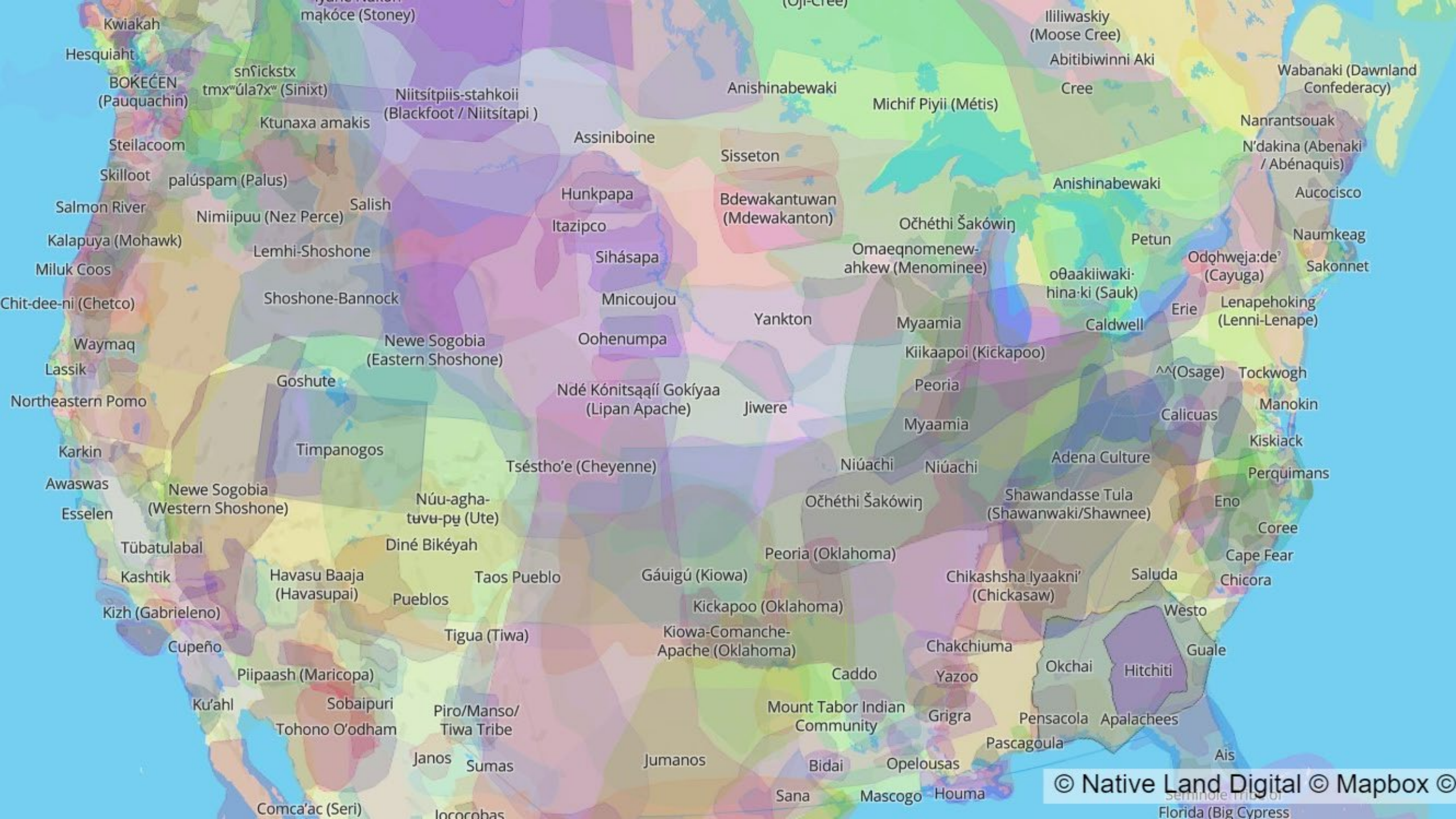
**There is no Health Equity
without Tribal Sovereignty**

U.S. LIFE EXPECTANCY AT BIRTH, PROVISIONAL MORTALITY DATA FOR 2021

The non-Hispanic American Indian and Alaska Native (AIAN) population experienced the largest decline in life expectancy between 2019 and 2021

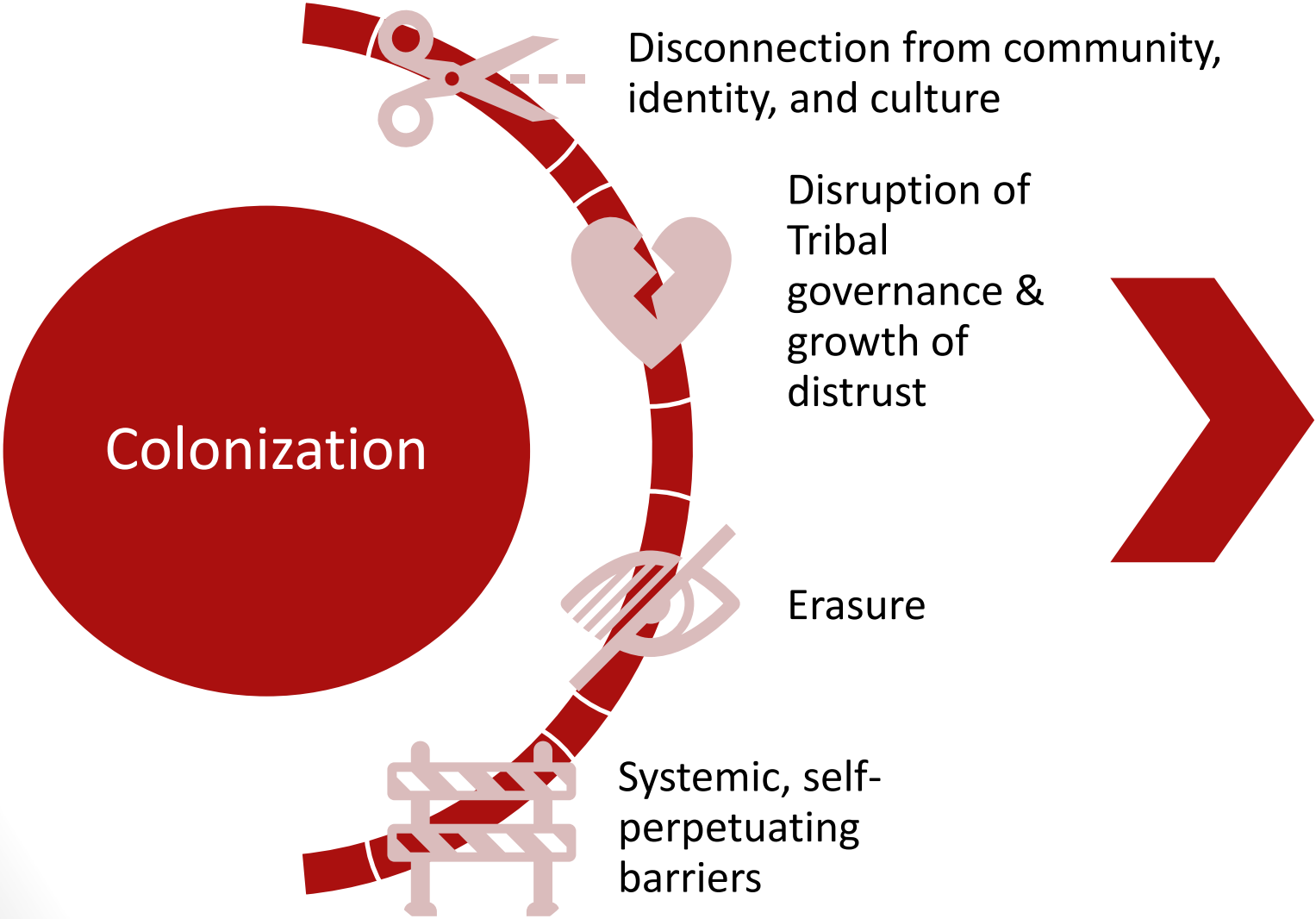
2021 US Avg (76.1)





Seminole Tribe of Florida (Big Cypress)

Roots of Health Inequities in Indian Country



Inequities in health outcomes for American Indians and Alaska Natives:

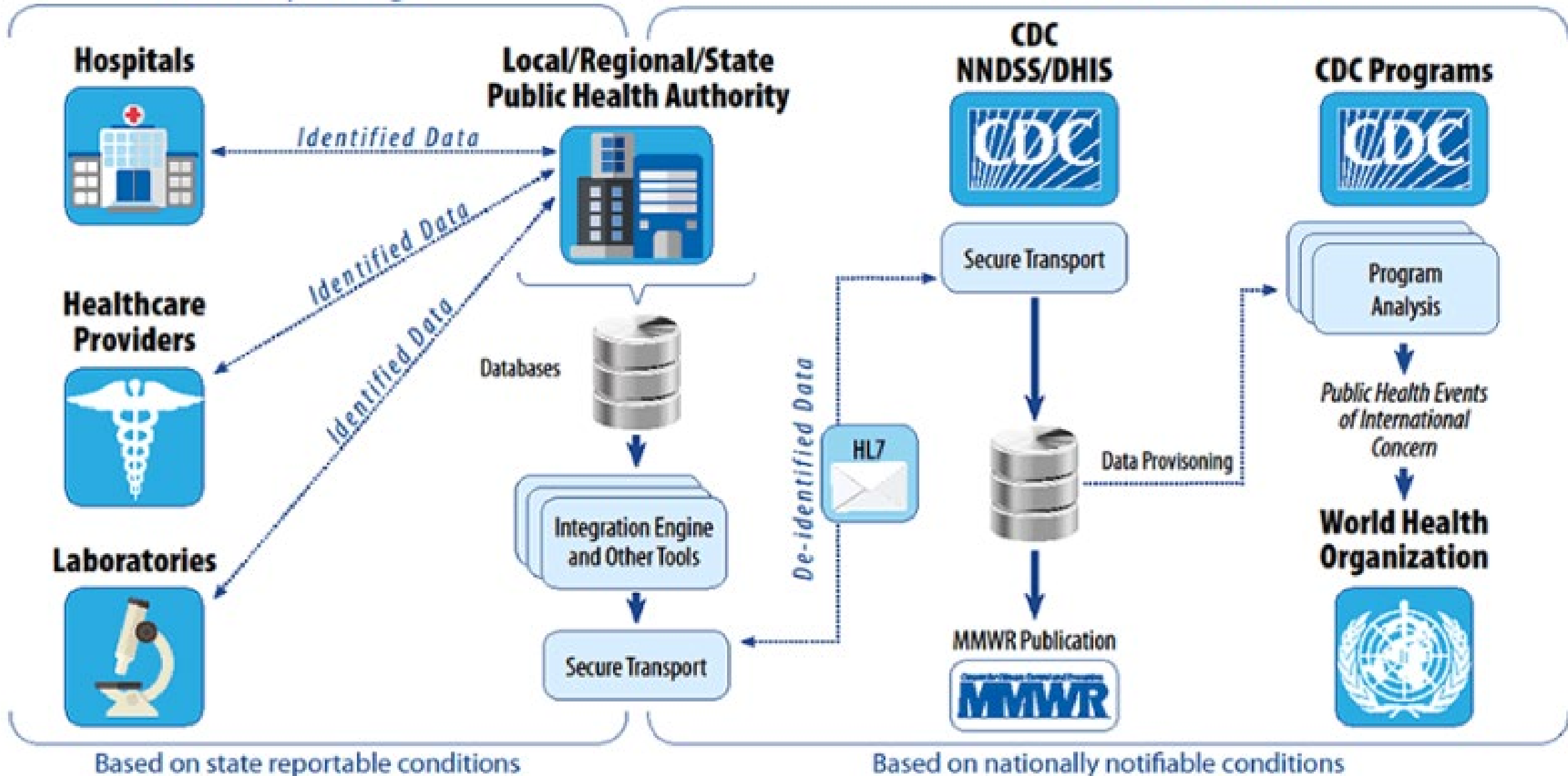
AI/AN life expectancy is now 11 years less than for the general American population

- Public Health is charged with addressing health equity and protecting the public's health and wellbeing
- **Public health data** are necessary to identify, respond to, and mitigate public health threats

National Notifiable Diseases Surveillance System Data Flow

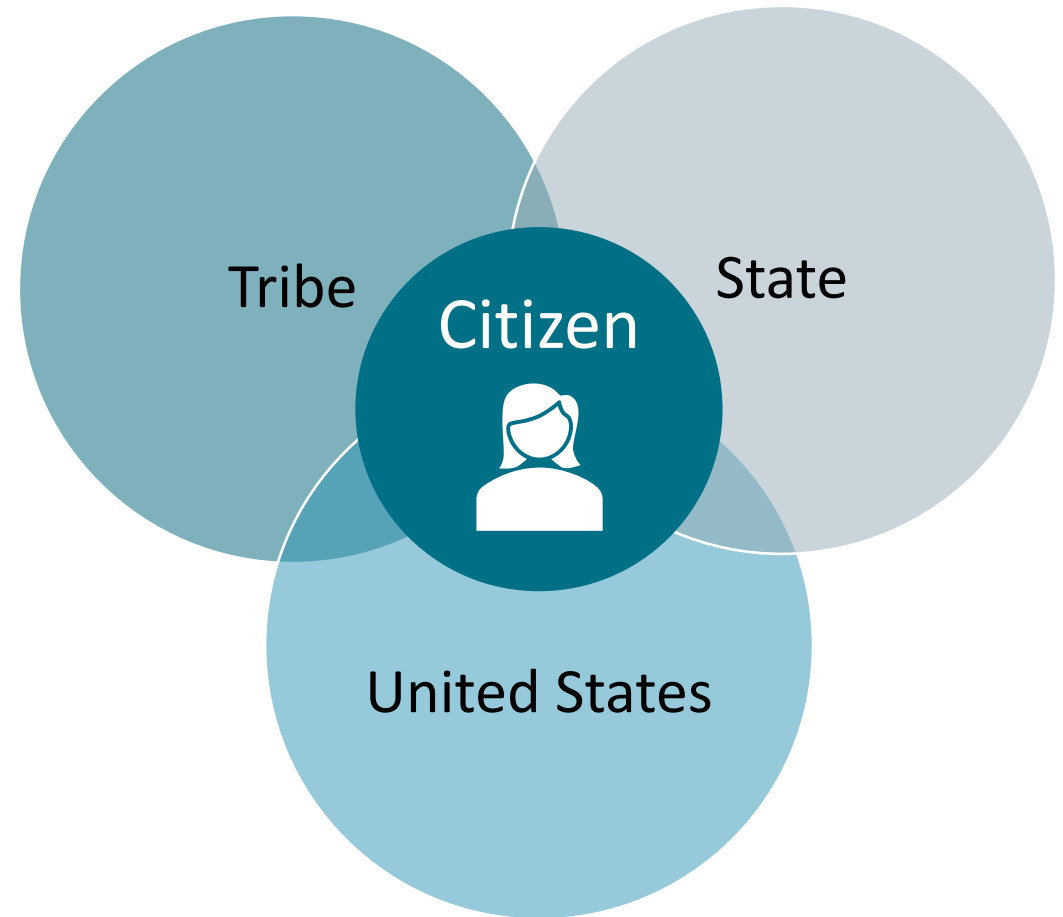
Case Reporting

Case Notification



Public Health System in Indian Country

- Services provided by:
 - Tribes
 - Indian Health Service
 - Tribal Epidemiology Centers
 - States
 - Counties
 - CDC



- Tribal public health is often integrated within healthcare systems.
- Strong linkages between public health and healthcare can strengthen systems.
- Tribal systems often follow a different (but equally effective) model compared to state and local health departments



FIGURE 1-2 Degrees of integration.





What kinds of data do Tribes need?

- Reportable disease data (infectious disease, STI, cancer)
- Birth and death records
- Environmental data
- Vaccine records
- Medicare and Medicaid claims data
- Injury and accident data
- Maternal morbidity and mortality data
- Census data
- ...and many more

Challenges in Tribal Access to Public Health Data

Public health data are necessary to identify, respond to, and mitigate public health threats

Data are often held by non-Tribal governments and institutions and are not always representative of or available to American Indian and Alaska Native public health systems.

Federal, state, and local governments have not consistently upheld or supported Tribes' rights to access data, and Tribes are not always fully integrated into their surveillance systems, other public health data systems, or networks.

Without real-time access to accurate public health data, Tribes cannot adequately track the spread of disease, make data-informed decisions, identify those at high risk for severe illness or mortality, or evaluate prevention and other public health interventions.



Federal Indian Law 101





Legal & Systems Challenges to Data Access

- Exclusion from data systems
- Overlapping jurisdictional boundaries
- Misunderstandings of HIPAA and Public Health Authority
- State privacy and data sharing laws
- Lack of respect/recognition of Tribal sovereignty in practice
- **ATTORNEYS**

Tribal Nations – The Oldest Governments in North America

- When the first colonists arrived, they encountered a continent that was already settled by existing sovereign nations.
- Doctrine of Discovery
- This was recognized in Article I, Section 8, Clause 3 of the U.S. Constitution, which states that the United States Congress shall have power "To regulate Commerce with foreign Nations, and among the several States, and with the Indian Tribes."



Principals of Federal Indian Law

Framework of law that governs the rights, relationships, and responsibilities between Tribes, States, and Federal government

- **Recognizes Tribal Sovereignty**, tribes retain all of their inherent sovereignty that the federal government has not encroached upon
- **Federal plenary power**—Congress maintains authority to legislate on all matters concerning Tribes, NOT STATES
- **Government-to-Government**—the federal government, and not states, is in charge of Indian affairs—state law can have no force in Indian Country
- **Federal Trust Responsibility**--federal government has assumed a trust responsibility towards Indian nations, resulting from treaty language and from the role it has assumed with respect to limiting Tribal sovereignty.

Tribal Sovereignty

*The right and power to
self-govern*

- **Tribes are sovereign nations**, with the power and duty to safeguard their citizens' health
- **Tribal nations predate the formation of the United States** – they retain their sovereignty
- **Tribal sovereignty has been repeatedly recognized and affirmed** by the U.S. Supreme Court, the U.S. Constitution, and hundreds of Indian treaties and federal statutes
- Tribal nations hold a **unique *government-to-government* relationship with the United States (NOT STATES)**
- **“American Indian/Alaska Native”** is first and foremost a **political status**
- **Recognized NOT Granted, unlike States**

The Three Governments: Tribal, Federal, & State



It is the obligation of the federal government to protect tribal self-governance, lands, assets, resources, and treaty rights, and to carry out the directions of federal statutes and court cases.

Federal Trust Responsibility



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



The provision of services such as health care was included in treaties that Tribes signed with the United States in exchange for giving up their lands.



The trust responsibility is a “fiduciary obligation . . . to protect [T]ribal treaty rights, lands, assets, and resources, as well as a duty to carry out the mandates of federal [Indian] law.”

Treaties & Provision of Health



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.



Snyder Act (1921)—Authorized Tribal-specific health care funding



Transfer Act (1954)—the Indian health program became a responsibility of the Public Health Service and recognized Tribal Sovereignty



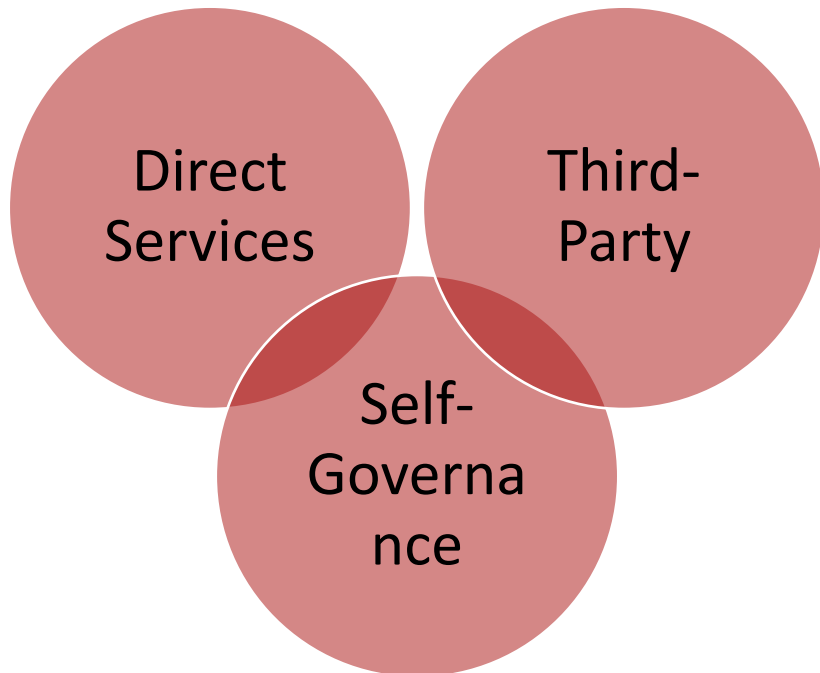
Many other laws and legally binding documents reaffirm these obligations.

Tribal Self-Determination

- **Self-determination**, simply means that Tribes themselves, rather than the federal government, decide funding priorities and manage Tribal resources.
- **Indian Self-Determination and Education Assistance Act (1975) [ISDEAA]**
 - Codified the principal of Tribal self-governance
 - Basis for authorizing Tribes to assume the management of BIA and IHS programs through Title V Compact and Title I Contract
 - Over half of IHS's budget is controlled by Tribes under this Act



Indian Health Care Improvement Act

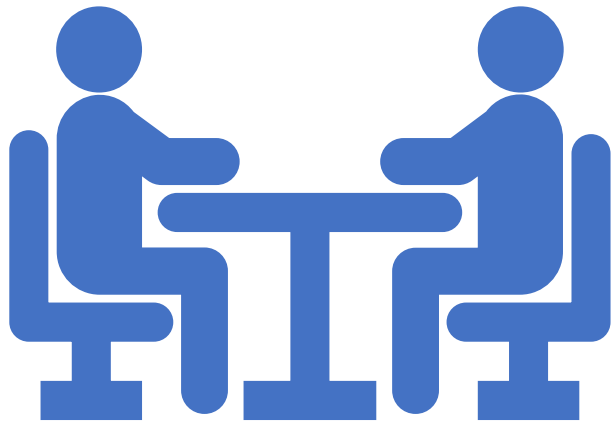


- Consolidated and increased funding for the Indian Health Service (IHS), provided services for urban Indians, and allowed Medicare and Medicaid to reimburse IHS
 - *Permanently reauthorized in the Affordable Care Act (2010).*
- Authorized the **establishment of Tribal epidemiology centers (TECs)** to serve Tribes across each Indian Health Service region throughout the United States



Indian Health Care Improvement Act

- “[I]t is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to Indians --[] to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy[.]” – 25 U.S.C 1602



Tribal Consultation: Government-to- Government

- Government agencies with data on AI/AN people have a responsibility to engage in government-to-government consultation with through Tribal Consultation
- 2021 Presidential Memorandum reaffirming Executive Order 13175, which directs federal agencies to “engage in regular, meaningful, and robust consultation with Tribal officials in the development of federal policies that have Tribal implications”

Federal Trust Responsibility for Health Care

INDIAN HEALTH SERVICE³⁹



APPROXIMATELY
2.56 Million

American Indians and Alaska Natives are served by the IHS, which operates a comprehensive health service delivery system.

The majority of those who receive IHS services live primarily on reservations and in rural communities in 37 states, mostly in the western United States and Alaska.



Percentage of IHS service area population residing in tribal areas

The IHS funds 41 urban Indian health organizations, which operate at sites located in cities throughout the United States.⁴⁰



600,000

Approximately 600,000 American Indians and Alaska Natives are eligible for programs in urban clinics.⁴¹

Legal Foundations of Public Health Data Sharing in Indian Country

Tribal Public Health Authority

Basis for government-to-government relations and data sharing with other PHA at federal, state, and local levels.



Inherent Public Health Authority



Designated Public Health Authority

Inherent Tribal Public Health Authority

- **No federal law** is needed to grant Tribes the authority to engage in public health activities.
- ***Parens patriae*** authority refers to a government's authority to intervene and implement strategies to protect the well-being of their community, like secondhand smoke laws.
- Tribes have inherent authority as sovereign nations to protect and promote the health and welfare of their citizens, using methods most relevant for their communities.
- Engaging in isolation, quarantine, case investigations, contact tracing, and disease surveillance are essential public health services. ***These powers are inherent to all sovereign nations, including Tribes.***

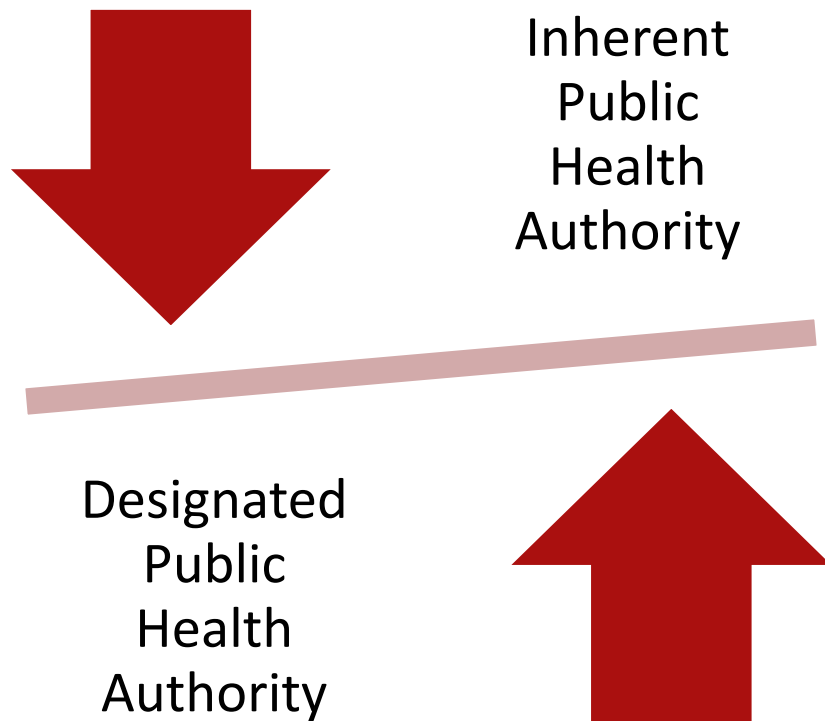
TECs: Designated Public Health Authority

- Tribal Epi Centers are also public health authorities for the purposes of HIPAA
- Charged with carrying out public health activities on behalf of the Tribes
- Specifically recognized in federal law as exempted from the data sharing restrictions in HIPAA



**TRIBAL
EPIDEMIOLOGY
CENTERS**

Tribal Public Health Authority



- Although the federal government defines Public Health Authority as part of statutory and regulatory schemes, **being recognized as a public health authority under a federal law is distinct from being the official public health authority for a sovereign government.**
- **For example**, HIPAA recognizes TECs as public health authorities for the purposes of access to protected health information. This does not, however, mean that TECs are the governmental public health authority of each Tribal sovereign nation it serves.

WHAT?? NO DEFINITION FOR PHA?



- No Statutory Definition of “Public Health Authority”
- A **Health Oversight Agency** is defined by federal law (45 CFR 164.501) as:

“an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an **Indian tribe**, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, **that is responsible for public health matters as part of its official mandate.**”

Data Sovereignty



In mainstream usage, “data sovereignty is the concept that information which has been converted and stored in binary digital form is subject to the laws of the country in which it is located.”



“**Indigenous data sovereignty** is the right of Native nations to govern the collection, ownership, and application of its own data.”

Core Tribal Data Sovereignty Principals

Only a Tribe has the sovereign authority to determine how their data may or may not be used.

“When a jurisdiction reports on or about American Indian or Alaska Native peoples, it should meaningfully partner and consult with Tribal leaders on the analysis and interpretation of the data.”

Tribes retain an ownership interest in data, even when the Tribe’s data are located in a state, federal or other dataset. This interest remains when the Tribe’s data are aggregated with other data.

Tribes must have equitable access to data needed to perform their governmental duties.

Major Barriers to Tribal Data Access

- Exclusion of Tribal nations from decision-making/input on federal and state government use of tribal and AI/AN data.
- Lack of federal and state data sharing agreements that protect Tribal and AI/AN data and recognize Tribal ownership in data about their Tribe and their people.
- Lack of federal and state government mechanisms to provide Tribal nations equitable access to AI/AN data necessary for Tribes to perform their governmental duties
- Failure of public health laws to respect & support Tribal sovereignty and Tribe's inherent authority.



March 2022

TRIBAL EPIDEMIOLOGY CENTERS

HHS Actions Needed to Enhance Data Access

GAO-22-104698

2022 GAO Report: Enforcing current federal law

- “The Secretary shall grant to each [Tribal] epidemiology center... access to use of the data, data sets, monitoring systems, delivery systems, and other protected health information in the possession of the Secretary.” (Indian Health Care Improvement Act, 2010)
- GAO recommendations:
 - HHS should clarify the data it will make available to TECs as required by federal law
 - CDC and IHS should develop guidance on how TECs should request data, and
 - Develop agency procedures on responding to such requests

Electronic Case Reporting, Infectious Disease Surveillance, and Data Sovereignty

Data challenges and disease surveillance:

- Tribes and TECs face significant barriers in accessing public health data.
- TECs have had to wait months or years to receive the data they need.
- COVID-19 data was delayed up to 7 months during the pandemic-hindering emergency response efforts.
- This has real world consequences- Tribes cannot make informed decisions about community health needs without data.

-Source: US GAO Report 2022

Data Sharing Varies by State

- Tribal access to data varies on a state-by state basis.
- Many states have laws or policies limiting Tribal data sovereignty (often unintentionally or due to misunderstandings).
- This is despite clear federal recognition that Tribes are public health authorities.

What is Electronic Case Reporting (eCR)?

- The automated, real-time exchange of disease case reports between electronic health records (EHRs) and public health authorities.

eCR provides:

- Real time surveillance
- Faster outbreak response
- Better communication between healthcare and public health

HOW DOES ELECTRONIC CASE REPORTING (eCR) WORK?



Patient is diagnosed with a reportable condition, such as COVID-19



Healthcare provider enters patient's information into the electronic health record (EHR)



Data in the EHR automatically triggers a case report that is validated and sent to the appropriate public health agency if it meets reportability criteria



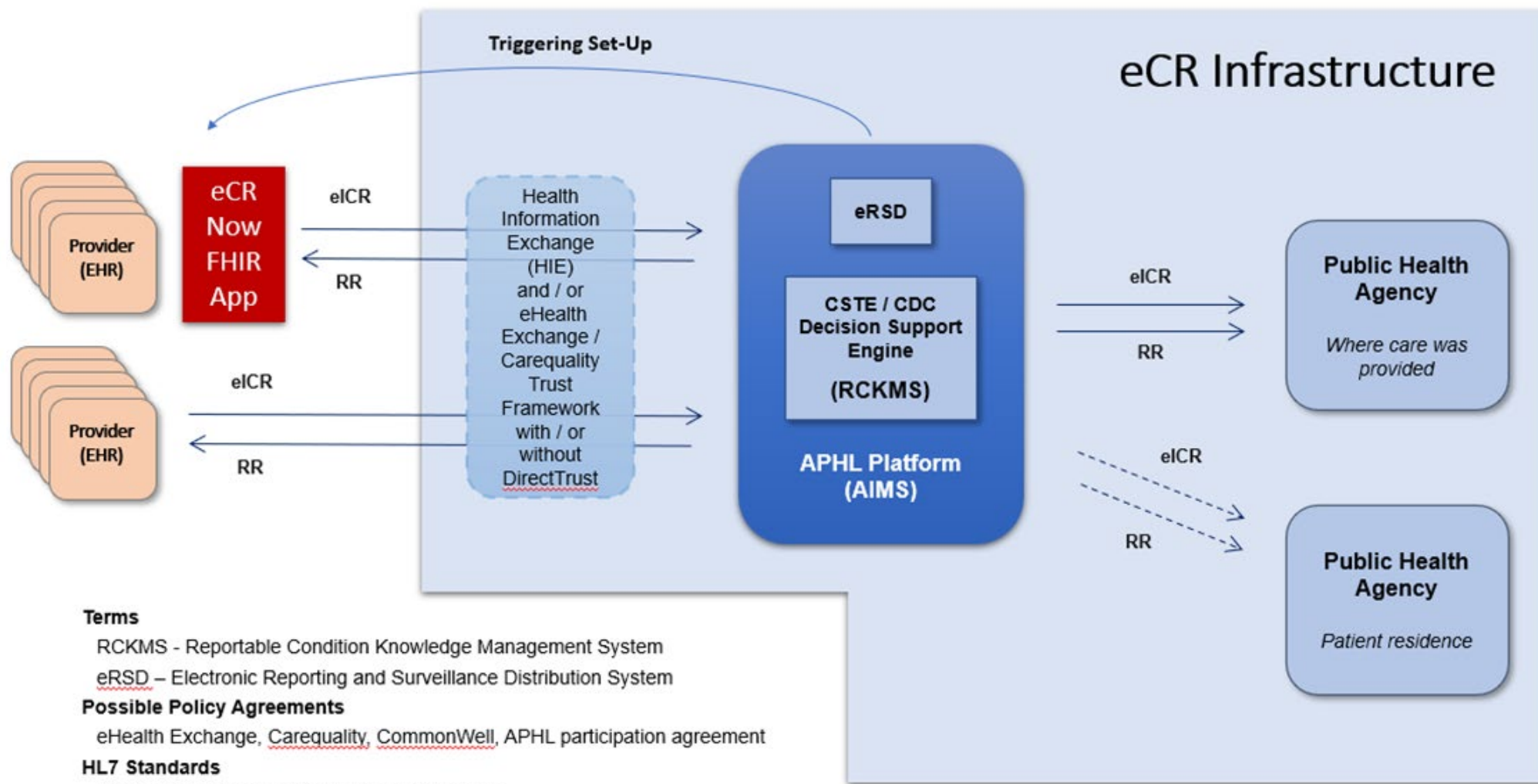
The public health agency receives the case report in real time and a response about reportability is sent back to the provider



Public health agency reaches out to patient for contact tracing, services, or other public health action



cdc.gov/eCR



Terms

RCKMS - Reportable Condition Knowledge Management System
 eRSD – Electronic Reporting and Surveillance Distribution System

Possible Policy Agreements

eHealth Exchange, Carequality, CommonWell, APHL participation agreement

HL7 Standards

eICR - Electronic Initial Case Report CDA v1.1
 RR - Reportability Response CDA v1.0

Source: CDC eCR Team

eCR Challenges

- Zip code overlap across jurisdictions
- Tribal citizens reside outside of Tribal land
- Public health departments, as a separate entity from healthcare, is new for many Tribes. Tribes must establish their health agencies as Public Health Authorities to engage with eCR.
- Funding sustainability
- EHR limitations

Progress Towards eCR

- Two pilot grantees are about to connect to the national eCR system, AIMS, and will begin receiving case reports.
- There has been some challenges in educating states and national agencies about Tribal public health authority.
- Tribes have had challenges on the ground documenting public health authority for the health department
- Pilot Tribes are leveraging eCR as a first step for better data sharing

**Bringing it All Together: Data, Health Equity,
and Paths Forward**



Where do we go from here?

- Achieving health equity means re-creating our public health system to restore power to Tribes and honor Tribal sovereignty
- Also requires investment & capacity building in Tribal Public Health Infrastructure
 - Tribal Public Health Codes, Codifying Public Health Authority
 - Data Systems, Modern EHR
 - Epidemiologists & Statisticians
- Tribes are the experts in Tribal health equity.
 - Tribes know what their communities need
 - With resources, data, and government-to-government collaboration, Tribal public health can lead the way to health equity

Where do we go from here?

- Working with Tribes must have a foundation of respect for Tribal sovereignty, including data sovereignty
- Remember that Tribes have good reasons for protectiveness over their data & citizens
- Building strong partnerships between Tribe and state/local health departments takes time, effort, and good faith – it's also necessary for meaningfully advancing health equity



There is no Health Equity
without Tribal Sovereignty





What can states do to support health equity through Tribal data access?

- State laws cannot infringe on Tribal sovereignty.
 - Interpret state privacy laws as permissively as possible – data sharing with Tribes is part of respecting Tribal sovereignty
 - Remember, any allowances for “public health authorities” apply to Tribes and TECs, regardless of whether they are specifically named
 - If state law cannot be interpreted to allow for such sharing with Tribes or TECs, engage in efforts to amend the law to properly honor Tribal sovereignty
-

FEDERAL, STATE, & LOCAL POLICY & PRACTICE



Privacy officers, attorneys, and other experts should work with public health staff to outline how data can be shared – with minimal red tape

Take a stance of “Getting to Yes”
Clear, standardized processes benefit everyone



Tribes should have access to any data necessary to monitor and respond to public health threats

AI/AN and non-AI/AN people on or near Tribal lands
Tribal members living off Tribal lands



Policies to protect Tribal data sovereignty



Tribal Consultation Policies

Tribal Consultation Policies are a powerful tool for advancing health equity and honoring Tribal sovereignty.

Timely, Meaningful, and Robust Tribal Consultation

- Tribal consultation is required when:
 - A federal or state agency is considering a policy change that could affect Tribes, Tribal lands, or Tribal citizens
 - A government agency is collecting data that includes Tribal citizens
 - A Tribe requests consultation
- Government-to-Government diplomacy & collaboration
- Decision-makers need to be at the table
- Before a decision is made
- Transparent
- Free, informed, prior consent
- Report back how Tribal input was incorporated into the policy

Where to Start



Hold Tribal consultation to determine what data Tribes need



Identify what data you share, and what data you do not share



Determine what agreements are already in place with Tribes, and where agreements are missing



Work with your legal counsel and Tribal leadership/representatives to overcome barriers and get to yes

Discussion Questions:

- Have you ever engaged in public health data sharing between a Tribe and another agency (i.e. state or local health department, federal agency)?
- What barriers do you face in sharing public health data between Tribes and non-Tribal agencies?
- What information do you need to be able to successfully advocate for improving public data sharing with Tribes?

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THANK YOU