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2025 California Healthcare Best Practices Conference

Indigenous Data Sovereignty and Governance for Tribal Health Data

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Cancer Health Researcher
University of California, Davis

Session Overview

- **Part 1:** What is Indigenous Data Sovereignty and Governance
- **Part 2:** Why is Indigenous Data Sovereignty and Governance critical for Tribal health data
- **Part 3:** Current examples and efforts to integrate Indigenous Data Sovereignty and Governance into Tribal data management

2025 California Healthcare Best Practices Conference

Indigenous Data Sovereignty and Governance for Tribal Health Data

PART 1:

What is Indigenous Data Sovereignty and Governance

Indigenous Data Sovereignty: Meeting the Expectation

Indigenous Data:

All data generated by Indigenous Peoples (e.g., cultural and traditional knowledge) and data on or about Indigenous Peoples and territories.



Indigenous Data Sovereignty: Meeting the Expectation

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All data generated by Indigenous Peoples (e.g., cultural and traditional knowledge) and data on or about Indigenous Peoples and territories.

- This includes information about their environment, lands, and non-human relatives.



Indigenous Data Sovereignty: Meeting the Expectation

Indigenous Data:

All data generated by Indigenous Peoples (e.g., cultural and traditional knowledge) and data on or about Indigenous Peoples and territories.

- This includes information about their environment, lands, and non-human relatives.
- Indigenous data sources can range from artwork, storytelling, practices, and ceremonies to biospecimens, ancestral remains, and genomic data.



Indigenous Data Sovereignty: Meeting the Expectation

Indigenous Data:



Indigenous Data Sovereignty (IDSov):

The right of Indigenous Peoples and nations to govern the collection, ownership, and application of their own data.

Indigenous Data Sovereignty: Meeting the Expectation

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Indigenous Data Sovereignty (IDSov):

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Recognized internationally in the 2007 United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)

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Indigenous Data Sovereignty (IDSov):

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Indigenous Data Governance (IDGov)

The policies, regulations, laws by which we exert Indigenous sovereignty over data

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Indigenous Data Sovereignty and Governance for Tribal Health Data

PART 2:

**Why is Indigenous Data Sovereignty and Governance critical for
Tribal health data**

The Power of Data to Inform Best Health Practices

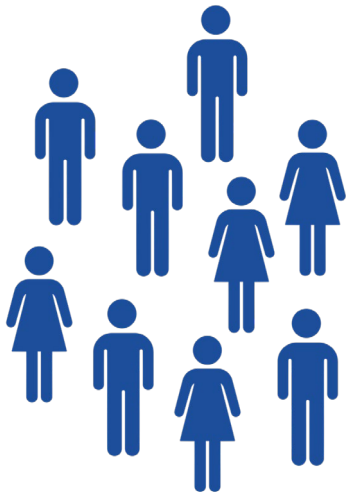
Research/Pilot Cohort



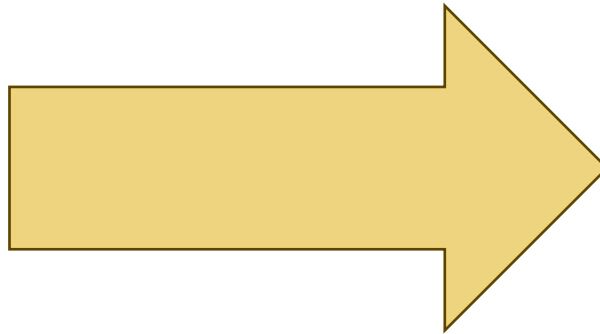
Representation matters – If our communities are not included among health research studies and pilot projects participants, we cannot benefit from the discoveries and health care advances of those studies and projects

The Power of Data to Inform Best Health Practices

Research/Pilot Cohort



Improve health care



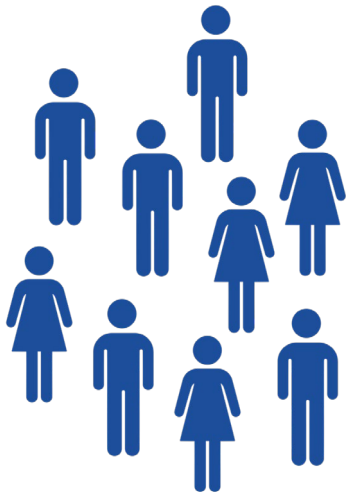
Best practices

New medical technologies for
prevention and treatment

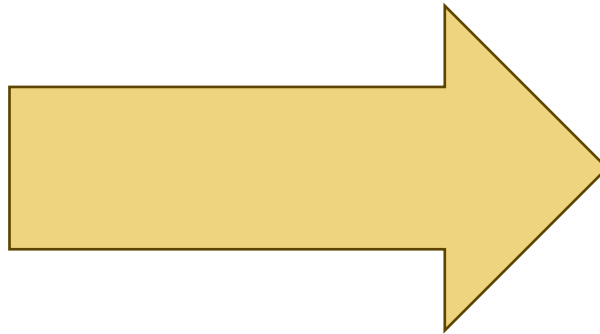
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The Power of Data to Inform Best Health Practices

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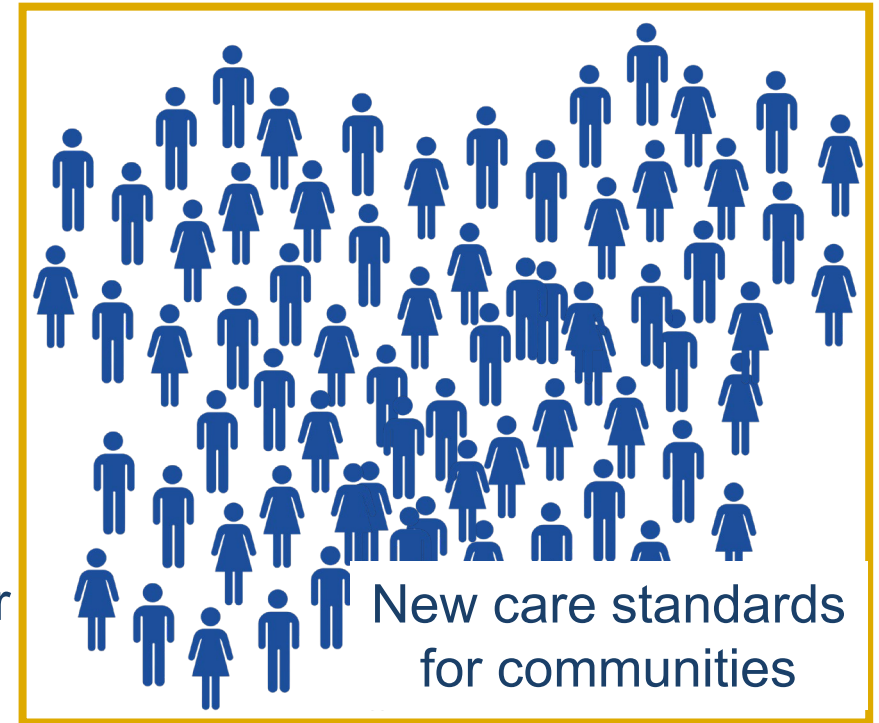


Improve health care



Best practices

New medical technologies for prevention and treatment



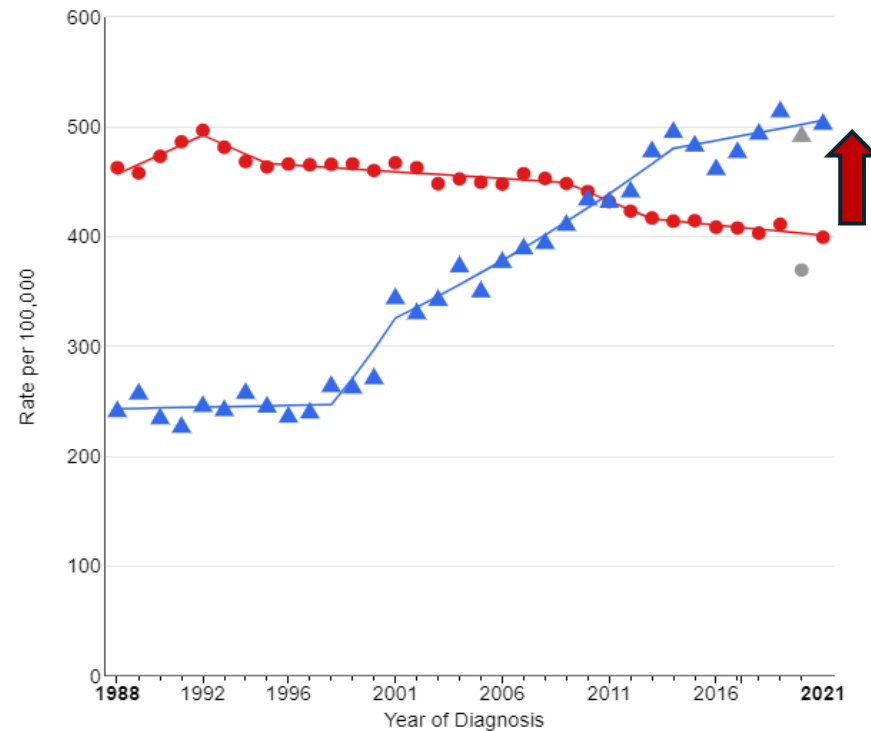
New care standards for communities

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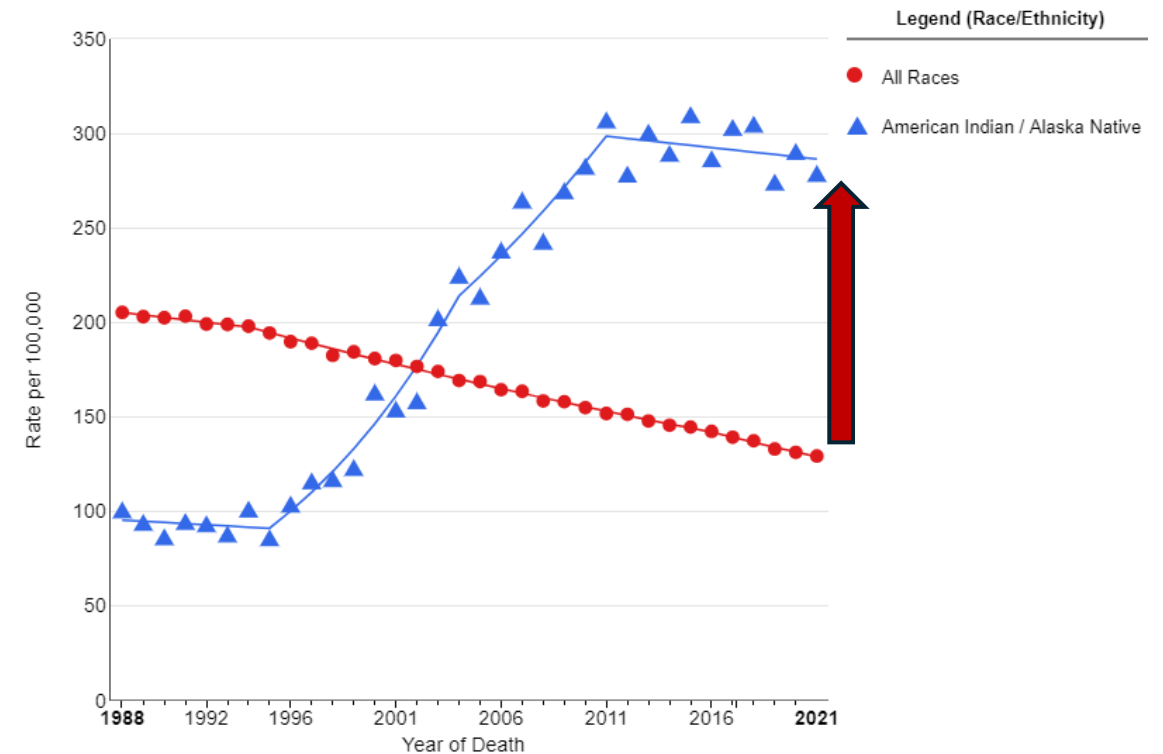
The Need for Accurate and Ethically-Managed Tribal Health Data

Cancer is a significant health problem for American Indians and Alaska Natives living in California

All Cancer Sites Combined
Trends in Incidence Rates, 1988-2021
By Race/Ethnicity, Both Sexes, All Ages, California



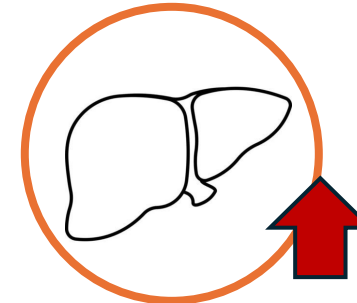
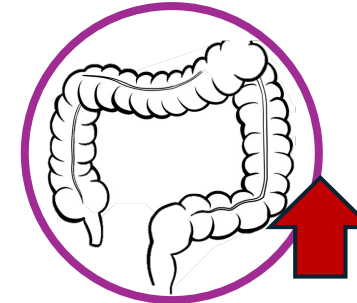
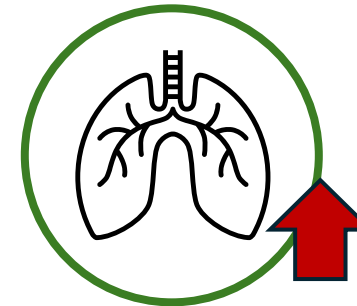
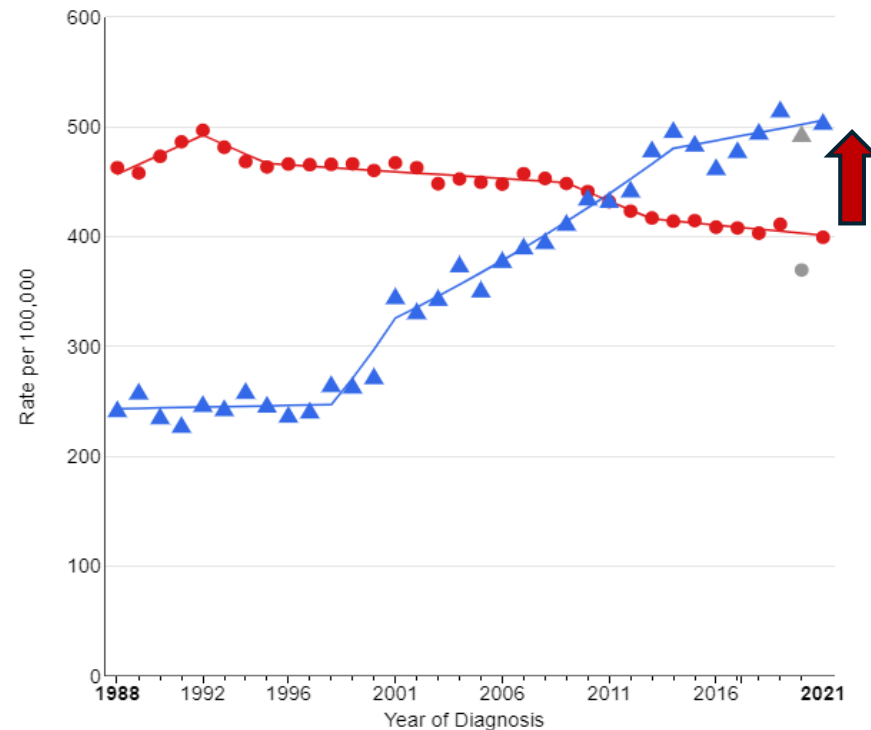
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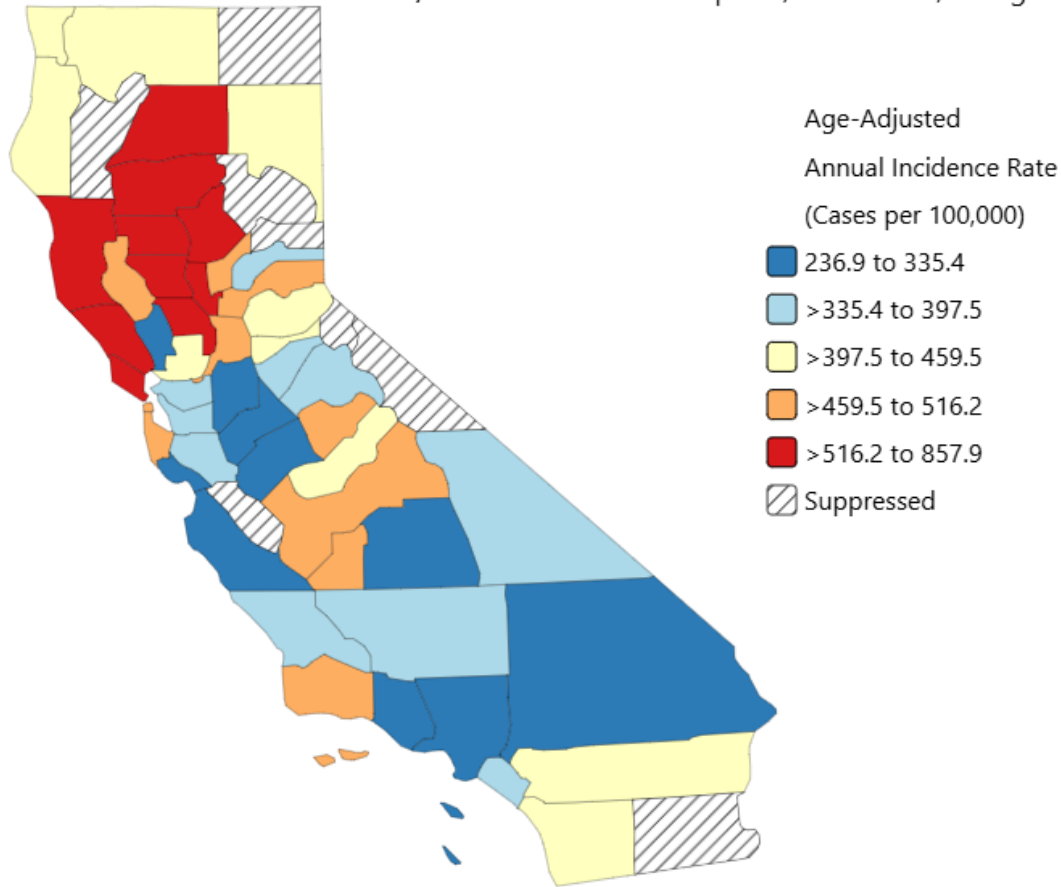


The Need for Accurate and Ethically-Managed Tribal Health Data

Incidence Rates for California by County

All Cancer Sites (All Stages^), 2017-2021

American Indian/Alaska Native Non-Hispanic, Both Sexes, All Ages

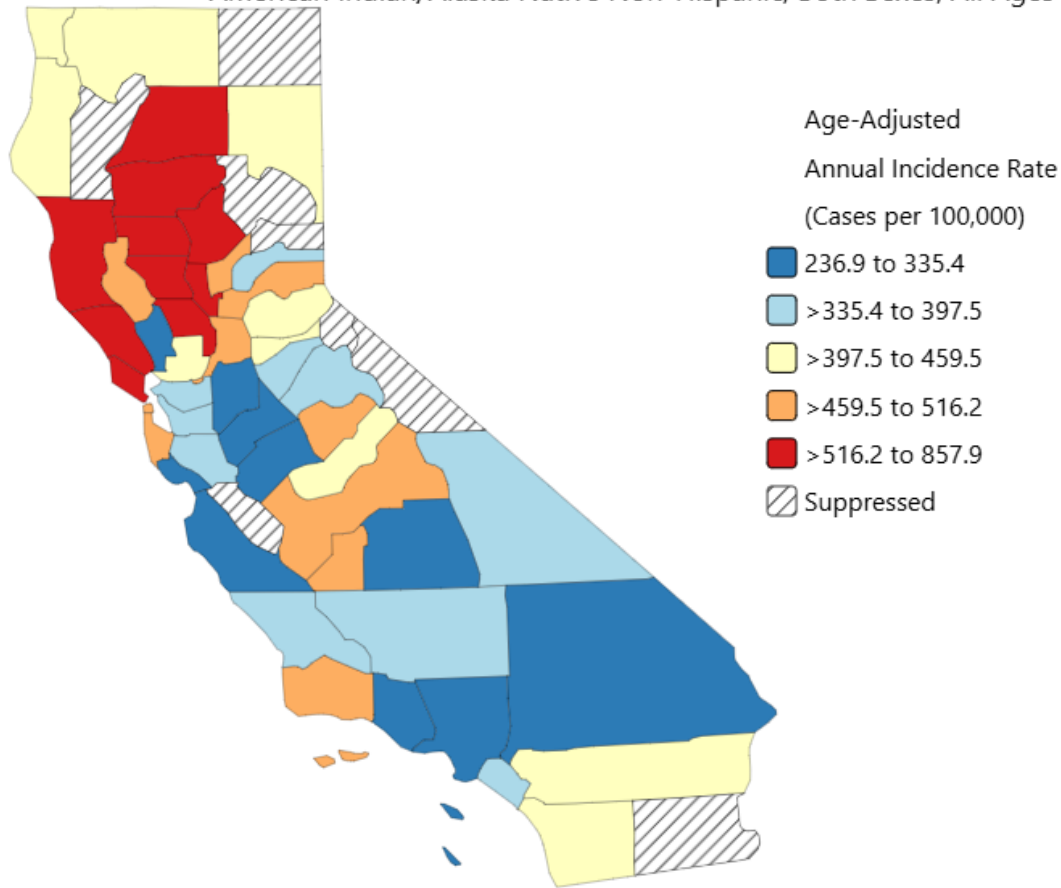


The Need for Accurate and Ethically-Managed Tribal Health Data

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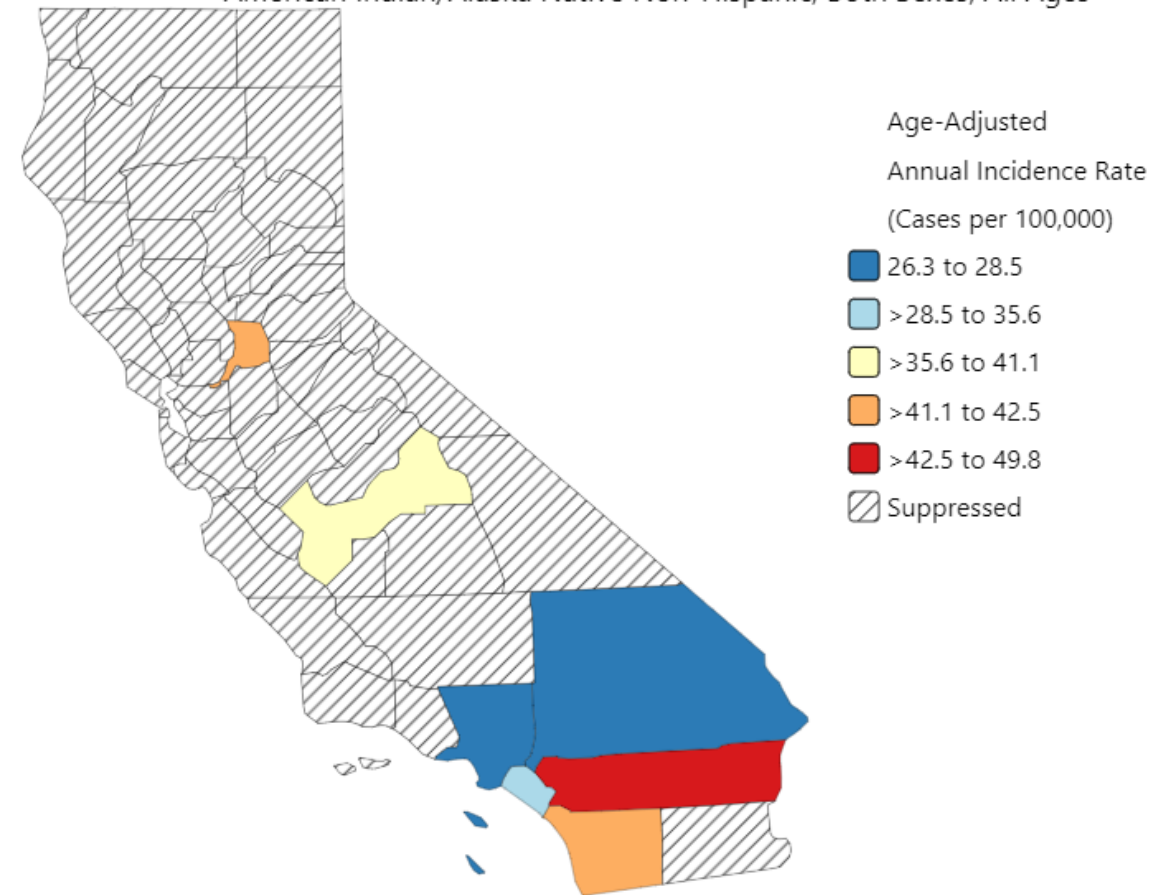
American Indian/Alaska Native Non-Hispanic, Both Sexes, All Ages



Incidence Rates for California by County

Colon & Rectum (All Stages^), 2017-2021

American Indian/Alaska Native Non-Hispanic, Both Sexes, All Ages



The Need for Accurate and Ethically-Managed Tribal Health Data

RESEARCH AND PRACTICE

Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area

Melissa A. Jim, MPH, Elizabeth Arias, PhD, Dean S. Seneca, MPH, MCURP, Megan J. Hoopes, MPH, Cheyenne C. Jim, MS, Norman J. Johnson, PhD, and Charles L. Wiggins, PhD

National Databases
Cancer Registries



IHS Hospitals/Care
Facilities records

Linkage

The Need for Accurate and Ethically-Managed Tribal Health Data

RESEARCH AND PRACTICE

TABLE 3—Sensitivity and Classification Ratios for Cases That Linked to IHS: NPCR-SEER Data, United States, 1990–2009 (Table view)

Group	No. AI/AN CHSDA Cases		No. AI/AN Non-CHSDA Cases		Sensitivity ^a		Classification Ratio ^b	
	IHS	Registry	IHS	Registry	CHSDA	Non-CHSDA	CHSDA	Non-CHSDA
Male and Female ^c	11 351	8811	1202	469	77.6	39.0	1.29	2.56
Male	5233	4046	512	204	77.3	39.8	1.29	2.51
Female	6118	4765	690	265	77.9	38.4	1.28	2.6
Northern Plains ^c	2387	2106	416	297	88.2	71.4	1.13	1.4
Alaska ^d	1260	1253	NA	NA	99.4	NA	1.01	NA
Southern Plains ^c	3817	2144	296	41	56.2	13.9	1.78	7.22
Southwest ^c	2314	2062	57	36	89.1	63.2	1.12	1.58
Pacific Coast ^c	1228	1064	70	40	86.6	57.1	1.15	1.75
East ^c	345	182	363	55	52.8	15.2	1.9	6.6
Urban ^c	4593	3349	526	219	72.9	41.6	1.37	2.4
Rural ^c	6758	5462	292	152	80.8	52.1	1.24	1.92

Racial Misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area

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Linkage of national cancer registry (NCI SEER) to IHS data increased the total number of AIAN cancer cases by 156%

Note. AI/AN = American Indian and Alaska Native; CHSDA = Contract Health Service Delivery Areas; IHS = Indian Health Service; NA = not applicable; NPCR = National Program of Cancer Registries; SEER = Surveillance, Epidemiology and End Results. Analysis includes AI/AN persons of Hispanic origin. Registries used: (43 states) AK,^z AZ,^z AR, CT,^z DE, GA, HI, ID,^z IA,^z IN,^z KY, LA,^z ME,^z MD, MA,^z MI,^z MS,^z MO, MT,^z NE,^z NV,^z NH, NJ, NM,^z NY,^z NC,^z ND,^z OH, OK,^z OR,^z PA,^z RI,^z SC,^z SD,^z TN, TX,^z UT,^z VT, VA, WA,^z WV, WI,^z WY,^z (^zindicate states with at least 1 county designated as CHSDA). Analyses limited to cases who linked to IHS.

Source. Cancer registries in the Centers for Disease Control and Prevention's NPCR or the National Cancer Institute's SEER.

- ^a Percentage of IHS cases also coded as an AI/AN person in the cancer registry of all IHS cases.
- ^b Ratio of the total number of cases classified as an AI/AN person in IHS to the total number of cases classified as an AI/AN person in the cancer registry.
- ^c Indicates statistically significant differences ($P < .01$) between the number of AI/AN cases in CHSDA and non-CHSDA.
- ^d All counties are CHSDA counties.

Controlling the Narrative and the Outcome

Havasupai Tribe v. Arizona Board of Regents (2004):

- (1989) Tribe members donated DNA samples for a genetic research project on type 2 diabetes
- Tribe discovers that samples were being used for other studies, no consent given by donors – Tribe files lawsuit

Controlling the Narrative and the Outcome

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**Not enough to generate accurate health data for our people,
we must also control how that data is used and for what purposes.**

Controlling the Narrative and the Outcome

Tribes



Tribal
Epidemiology
Centers

Tribal Health
Programs



National Databases



Controlling the Narrative and the Outcome



National Databases



We must have reliable access to the health data about our communities in order to provide timely and focused health care.

COVID-19 Pandemic



IDSov and IDGov support the translation of Tribal Health Data into better Tribal Health Care

Indigenous Data Sovereignty ensures:

Return of benefits to participating communities

Health program capacity-building

Data controlled by the Tribes

IDSov and IDGov support the translation of Tribal Health Data into better Tribal Health Care

Indigenous Data Sovereignty ensures:

Return of benefits to participating communities

Health program capacity-building

Data controlled by the Tribes

IDSov is a determinant of health for Native communities

2025 California Healthcare Best Practices Conference

Indigenous Data Sovereignty and Governance for Tribal Health Data

PART 3:

**Efforts to operationalize Indigenous Data Sovereignty and
Governance into Tribal data management**

Frameworks for Data Generation, Sharing and Management: Community-Specific



French

FNIGC | CGIPN
First Nations Information Governance Centre
Le Centre de gouvernance de l'information des Premières Nations

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The First Nations Principles of OCAP[®]

The First Nations principles of ownership, control, access, and possession – more commonly known as OCAP[®] – assert that First Nations have control over data collection processes, and that they own and control how this information can be used.



OUR MĀORI DATA SOVEREIGNTY PRINCIPLES

TMR advocates for the realisation of Māori rights and interests in data, and for the ethical use of data to enhance the wellbeing of our people, language and culture. This Te Mana Raraunga (TMR) Brief provides a general overview of key Māori Data Sovereignty terms and principles.



TE MANA RARAUNGA
Māori Data Sovereignty Network

Read more here: [Te Mana Raraunga - Principles of Maori Data Sovereignty](#)

Principles of Māori Data Sovereignty

Te Mana Raraunga | Brief #1 | October 2018

01 Rangatiratanga | Authority

1.1 Control. Māori have an inherent right to exercise control over Māori data and Māori data ecosystems. This right includes, but is not limited to, the creation, collection, access, analysis, interpretation, management, security, dissemination, use and reuse of Māori data.

1.2 Jurisdiction. Decisions about the physical and virtual storage of Māori data shall enhance control for current and future generations. Whenever possible, Māori data shall be stored in Aotearoa New Zealand.

1.3 Self-determination. Māori have the right to data that is relevant and empowers sustainable

04 Kotahitanga | Collective benefit

4.1 Benefit. Data ecosystems shall be designed and function in ways that enable Māori to derive individual and collective benefit.

4.2 Build capacity. Māori Data Sovereignty requires the development of a Māori workforce to enable the creation, collection, management, security, governance and application of data.

4.3 Connect. Connections between Māori and other Indigenous peoples shall be supported to enable the sharing of strategies, resources and ideas in relation to data, and the attainment of common goals.

Frameworks for Data Generation, Sharing and Management: Community-Specific

Critical for Tribes in the US to have data use and management policies, regulatory infrastructure in-place as multi-sourced data integration is becoming more common in the healthcare space

... | **Collective benefit**
... ecosystems shall be designed and that enable Māori to derive collective benefit.
... y, Māori Data Sovereignty requires the development of a Māori workforce to enable the creation, collection, management, security, governance and application of data.

- reuse of Māori data.
- 1.2 Jurisdiction.** Decisions about the physical and virtual storage of Māori data shall enhance control for current and future generations. Whenever possible, Māori data shall be stored in Aotearoa New Zealand.
- 1.3 Self-determination.** Māori have the right to data that is relevant and empowers sustainable...
- 4.3 Connect.** Connections between Māori and other Indigenous peoples shall be supported to enable the sharing of strategies, resources and ideas in relation to data, and the attainment of common goals.

Frameworks for Data Generation, Sharing and Management: Care Principles for all Indigenous Data



Centering *people* and *purpose* of data in research

Carroll, S, et al. 2020. The CARE Principles for Indigenous Data Governance. Data Science Journal, 19:43.

DATA PRINCIPLES						
INDIGENOUS				MAINSTREAM		
New Zealand Indigenous Data Sovereignty Principles	Australia Indigenous Data Sovereignty Protocols	United States Indigenous Data Governance Principles	Canada Indigenous Data Governance Principles	Open Data Charter Principles	FAIR Principles for Data Management and Stewardship	STREAM Properties for Industrial and Commoditized Data
Authority	Self-Determination	Inherent Sovereignty	OCAP®	Open By Default	Findable	Sovereign
Relationships	Available and Accessible	Indigenous Knowledge	Indigenous Knowledge	Timely and Comprehensive	Accessible	Trusted
Obligations	Collective Rights and Interests	Ethics	Methodology and Approaches	Accessible and Usable	Interoperable	Reusable
Collective Benefit	Accountability	Intergenerational Collective Wellbeing	Evidence to Build Policy	Comparable and Interoperable	Reusable	Exchangeable
Reciprocity	Exercise Control	Relationships	Ethical Relationships	For Improved Governance & Citizen Engagement		Actionable
Guardianship			Data Governance	For Inclusive Development and Innovation		Measurable
People oriented principles	Purpose oriented principles					

The CARE Principles



<https://www.gida-global.org/care>

Collective Benefit.

Data ecosystems shall be designed and function in ways that enable Indigenous Peoples to derive benefit from the data.

- C1. For inclusive development and innovation
- C2. For improved governance and citizen engagement
- C3. For equitable outcomes

Responsibility.

Those working with Indigenous data have a responsibility to share how those data are used to support Indigenous Peoples' self determination and collective benefit.

- R1. For positive relationships
- R2. For expanding capability and capacity
- R3. For Indigenous languages and worldviews

The CARE Principles



<https://www.gida-global.org/care>

Authority to Control.

Indigenous Peoples' rights and interests in Indigenous data must be recognized and their authority to control such data respected.

- A1. Recognizing rights and interests
- A2. Data for governance
- A3. Governance of data

Ethics.

Indigenous Peoples' rights and wellbeing should be the primary concern at all stages of the data life cycle and across the data ecosystem.

- E1. For minimizing harm and maximizing benefit
- E2. For justice
- E3. For future use

Examples of IDsov/Gov Operationalized in Tribal Health Data

Project ENABLE

Enriching Navajo As a Biology Language for Education

About The Project

Project ENABLE will facilitate the preservation and continued use of Diné Bizaad while also providing an opportunity to integrate traditional knowledge with current scientific thought and practices. We worked with high school biology teachers on Dinétah and a Diné language expert to identify and translate 245 terms that reflect foundational biology concepts into Diné bizaad.

Navajo Biology and Genetics Dictionary

<https://enablenavajo.org/>

Responsibility - Integrating Indigenous values and worldviews

Examples of ID Sov/Gov Operationalized in Tribal Health Data

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DNA

Definition: A long molecule that contains our unique genetic information. It holds the instructions for making all of the proteins in our bodies.

"Construction workers need instructions to know how to build a building. Cells use DNA as instructions to tell them what to do and how to make things."

iiná bit'óól

Literal translation: iiná = life, bit'óól = strand.
Meaning "strand of life"

Definition: Ats'íís bit'óól nineezgo hats'íís biyi'di hólónígíí bik'ehgo náás oochííhii yee hadít'é. Bik'ehgo ch'iyáán ats'íís ánáyoodlííhii proteins hats'íístahgóó hólónígíí nihwiileeh.

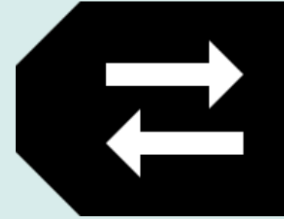
Responsibility - Integrating Indigenous value and worldviews

Examples of ID Sov/Gov Operationalized in Tribal Health Data



Provenance Labels

Provenance Labels identify the group or sub-group which is the primary cultural authority for the material, and/or recognizes other interest in the materials.



TK Attribution
(TK A)



TK Clan
(TK CL)



TK Family
(TK F)



TK Multiple
Communities
(TK MC)



TK Community Voice
(TK CV)



TK Creative
(TK CR)

Who owns the data/knowledge

Responsibility, Authority to Control, and Ethics

Examples of ID Sov/Gov Operationalized in Tribal Health Data



Protocol Labels
Protocol Labels outline traditional protocols associated with access to this material and invite viewers to respect community protocols.



TK Verified
(TK V)



TK Non-Verified
(TK NV)



TK Seasonal
(TK S)

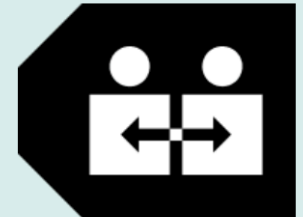
Who can access the data/ knowledge and when can they access it



TK Women General
(TK WG)



TK Men General
(TK MG)



TK Men Restricted
(TK MR)



TK Women Restricted
(TK WR)



TK Culturally Sensitive
(TK CS)



TK Secret / Sacred
(TK SS)

Responsibility, Authority to Control, and Ethics

Examples of ID Sov/Gov Operationalized in Tribal Health Data



Permission Labels

Permission Labels indicate what activities the community has approved as generally acceptable. Other uses require direct engagement with primary cultural authorities.



TK Open to Commercialization
(TK OC)



TK Non-Commercial
(TK NC)



TK Community Use Only
(TK CO)



TK Outreach
(TK O)

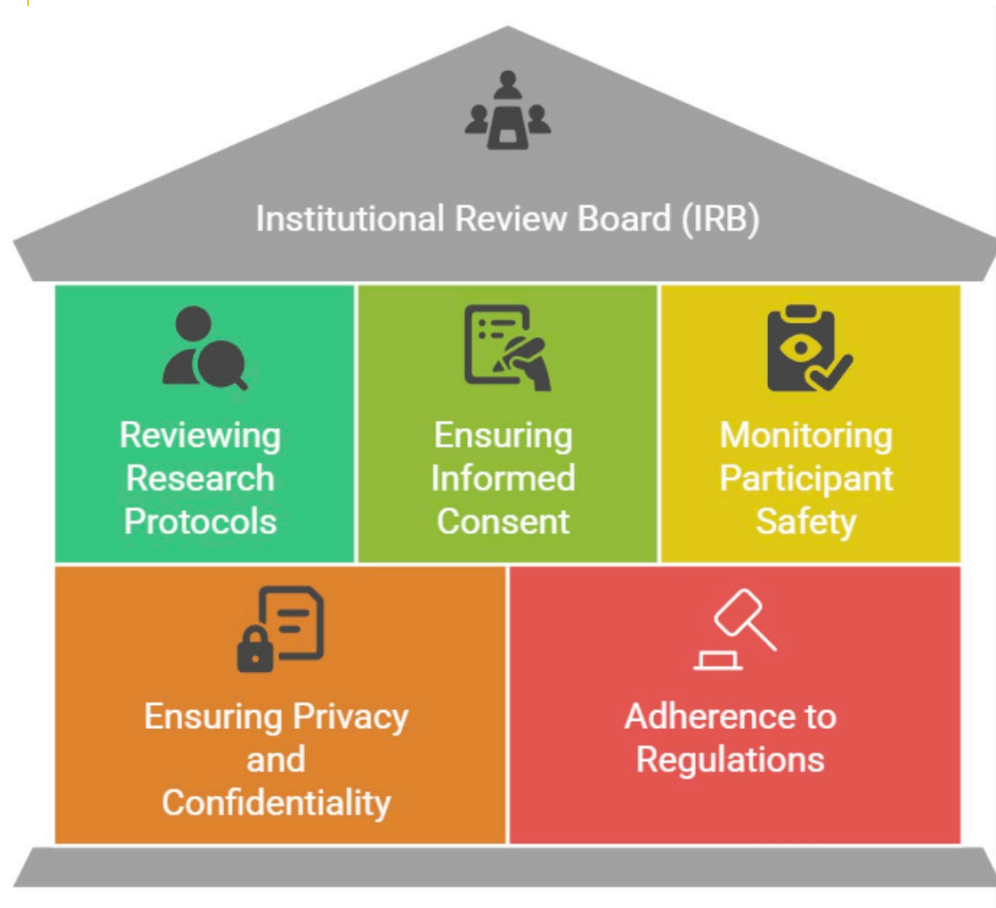


TK Open to Collaboration
(TK CB)

What can the data/knowledge be used for

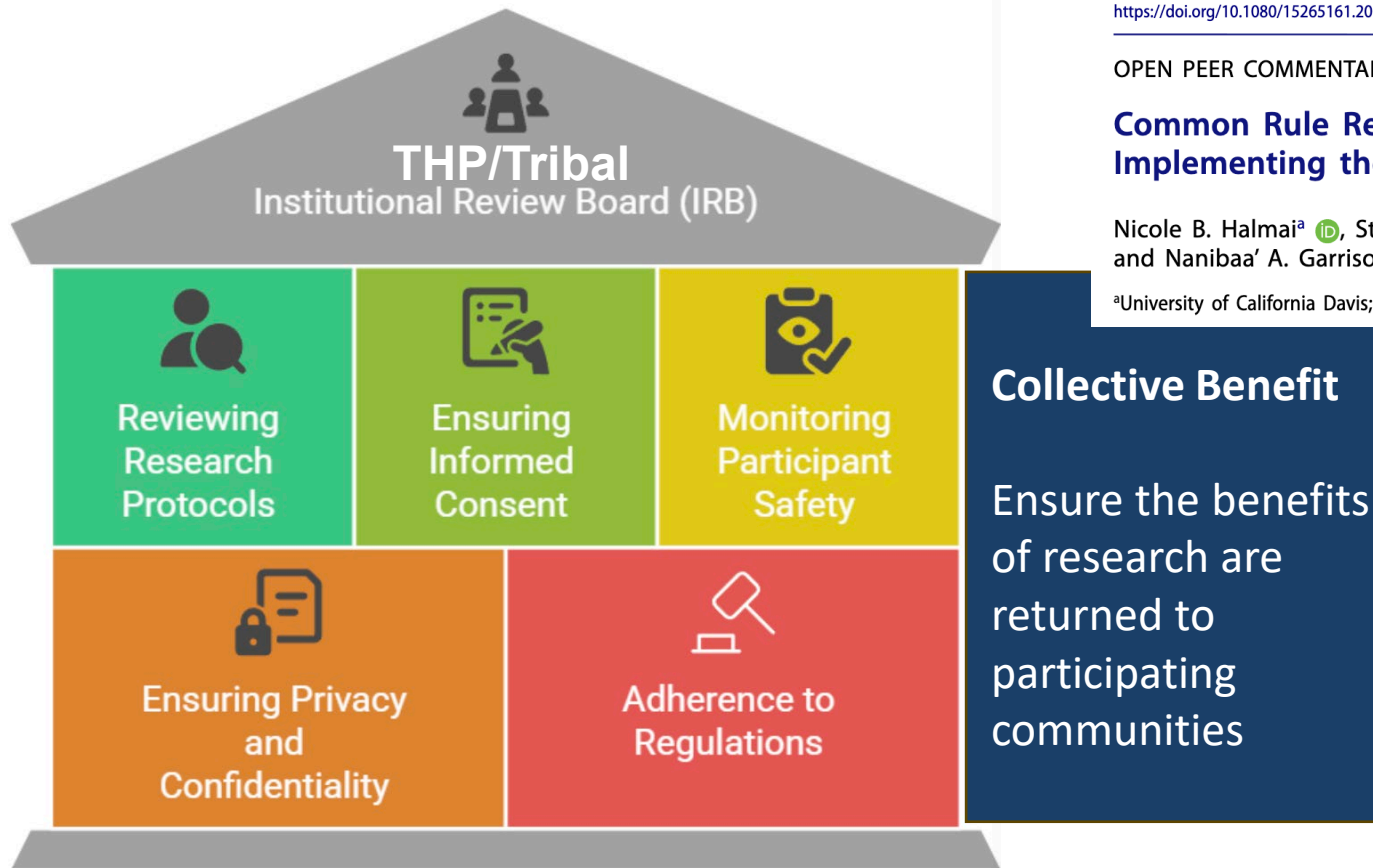
Responsibility, Authority to Control, and Ethics

Examples of IDsov/Gov Operationalized in Tribal Health Data



Collective Benefit – For capacity-building and equitable outcomes

Examples of IDsov/Gov Operationalized in Tribal Health Data



THE AMERICAN JOURNAL OF BIOETHICS
2025, VOL. 25, NO. 2, 73–76
<https://doi.org/10.1080/15265161.2024.2441737>



OPEN PEER COMMENTARIES

OPEN ACCESS

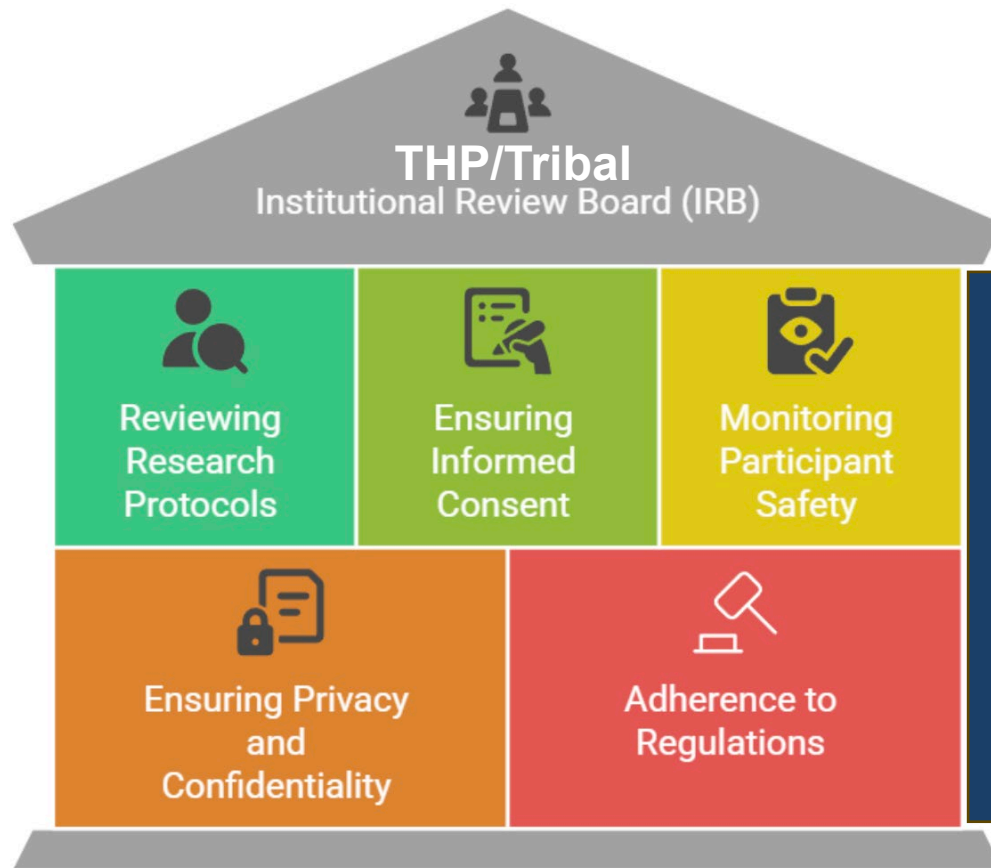
Common Rule Revisions to Govern Machine Learning on Indigenous Data: Implementing the Expectations

Nicole B. Halmai^a , Stephanie Russo Carroll^b , Ibrahim Garba^b , Joseph Manuel Yracheta^c and Nanibaa' A. Garrison^d

^aUniversity of California Davis; ^bUniversity of Arizona; ^cNative BioData Consortium; ^dUniversity of California Los Angeles

Collective Benefit – For capacity-building and equitable outcomes

Examples of IDsov/Gov Operationalized in Tribal Health Data



Collective Benefit

Ensure the benefits of research are returned to participating communities

THE AMERICAN JOURNAL OF BIOETHICS
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OPEN PEER COMMENTARIES

OPEN ACCESS [Check for updates](#)

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IRB for Full Members

Collective Benefit – For capacity-building and equitable outcomes

Examples of ID Sov/Gov Operationalized in Tribal Health Data

Biobanks



<https://www.nature.com/articles/d41586-018-06948-3>

Physical samples and data

Authority to Control – Control access to and physical storage of Tribal data

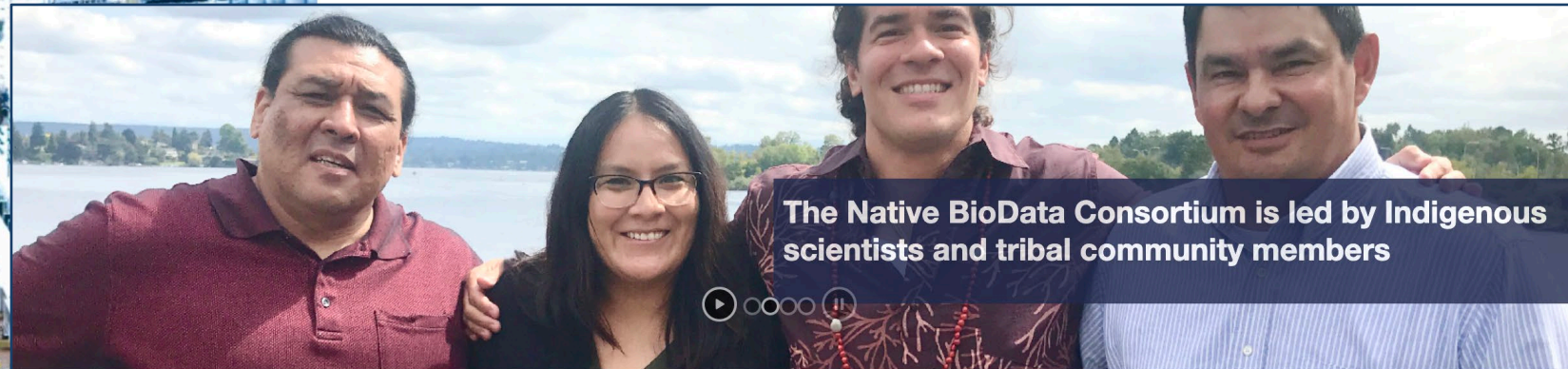
Examples of ID Sov/Gov Operationalized in Tribal Health Data

Examples of IDsov/Gov Operationalized in Tribal Health Data



Biobanks

Data storage/management/sharing capacity and policies



RESEARCH FOR NATIVES, BY NATIVES

The [Native BioData Consortium \(NBDC\)](#) 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”), we ensure that advances in genetics and health research benefit all Indigenous people.

Authority to Control – Control access to and physical storage of Tribal data

Key Takeaways for Moving Forward IDsov in Health

Data is power, accurate and available data is even greater power

- Identify and address health needs

Controlling the data narratives and the outcomes are key for improving Tribal health

- Our data has been used against us in the past, it should not continue to be in the future
- The future of healthcare is moving towards greater data integration

IDsov is a determinant of health for Native communities

- Frameworks provide the means to generate accurate data that Tribes can use to increase their health care capacity and efficacy

Points for Discussion

How are you thinking about IDsov for your Tribal Health Program?

Do you already have systems and infrastructure in place for greater data control?

- Storage (Physical and Virtual)
- Management and Sharing Protocols (Data Sharing Policies/Agreements)
- Research Review Boards

How are you utilizing the data your Tribal Health Program has generated?