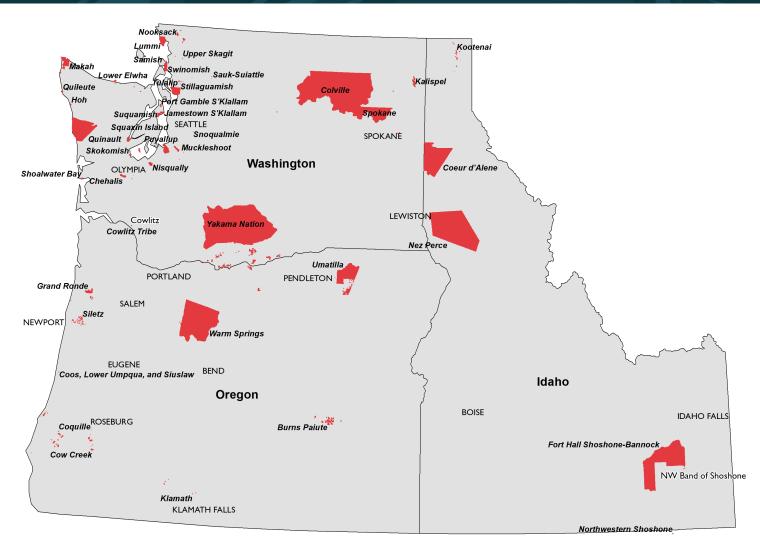
Moving Beyond Race and Ethnicity Data Collection to Define Al/AN Communities



Northwest Portland Area Indian Health Board



Vision: "Wellness for the seventh generation"

Guided by: Tribal Sovereignty, Traditional Indigenous Knowledge, Culture as Health Promotion



Visibility through data

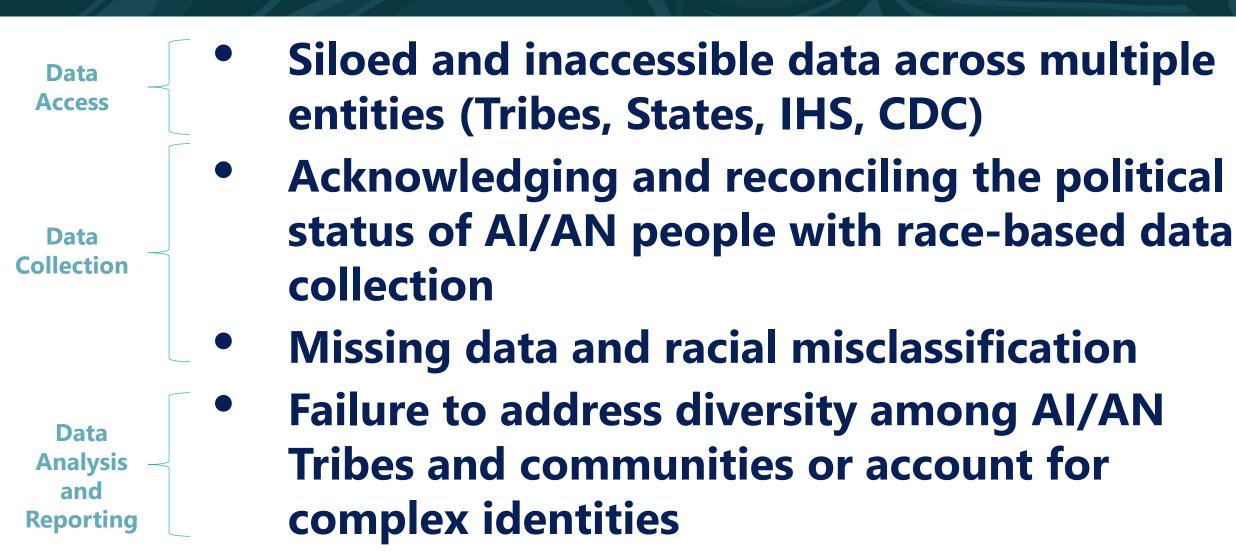
"Closing [economic and health disparity] gaps and addressing program and policy issues is complicated by the invisibility of American Indians and Alaska Natives in their own land.

It is not clear if invisibility results from lack of data or if lack of data leads to invisibility."

-Michelle Connolly (Blackfeet/Cree) et al, 2019, Statistical Journal of the IAOS 35(1)

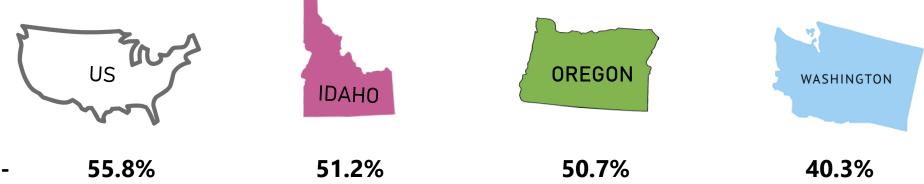


Health data challenges for AI/AN communities



Missing Data

Completeness of race and ethnicity data varies widely by data collection systems, region, and jurisdiction



% person-level Covid-19 cases reported to CDC with complete race and ethnicity information

Range across States

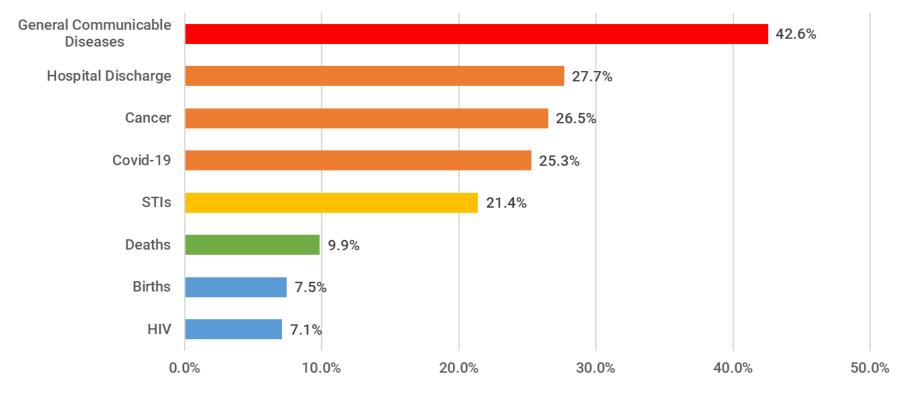
0% - 87.2%

Reference: Erickson S, Bokota R, Doroshenko C, Lewandowski K, Osei K, Flannery K, Dominguez A. Completeness of Race and Ethnicity Reporting in Person-Level COVID-19 Surveillance Data, 50 States, April 2020-December 2021. Public Health Rep. 2023 Mar 27:333549231154577. doi: 10.1177/00333549231154577.

AI/AN Misclassification

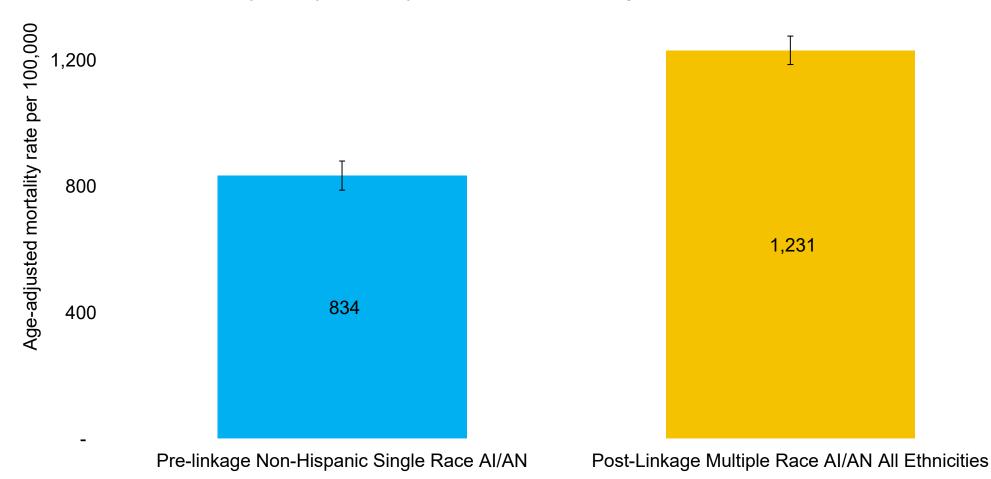
Misclassification happens when AI/AN people are recorded as being another race (usually White) in a dataset.

In the Northwest, AI/AN misclassification is highest in communicable disease, hospital discharge, and cancer data.



Defining AI/AN People

The most inclusive "definition" of Al/AN people (used by NWTEC) resulted in a 48% higher all-cause mortality rate in Washington compared to the least inclusive definition typically used by state and federal agencies.



Addressing Challenges

Siloed and Inaccessible Data

- Expand Tribal and TEC access to data held by state and federal agencies
- ✓ Develop a Northwest Tribal Data Hub to provide Tribes with data on their communities

Missing data and Misclassification

- ✓ Conduct record linkages between Tribal and State data to correct misclassified AI/AN records
- ✓ Support policies to improve accurate and complete data collection

Acknowledge diversity and complex identities

- ✓ Utilize inclusive ways of identifying and counting AI/AN people in data
- ✓ Support Tribal collection and analysis of data on their own communities

Acknowledge the political status of AI/AN people

- Educate partners on the rights of sovereign Tribes and the unique political status of Tribal members
- Engage in policy consultations and advocacy efforts related to state and federal data collection

OMB SPD-15

- The U.S. Office of Management and Budget is developing recommendations to revise Statistical Policy Directive No. 15, which sets standards for maintaining, collecting, and presenting federal data on race and ethnicity. These standards were last revised in 1997.
- Portland Area Tribes, individually and via NPAIHB, provided comments on the initial set of proposals through written comment and during a virtual tribal consultation session.

Key Recommendations

- Support moving from two questions to collect race and ethnicity to a single combined question for self-reported race and ethnicity
- Support AI/AN individuals being able to check their Tribal affiliation or community attachment as a detailed category level, preferably through drop down lists of federally recognized Tribes
- Suggest the ability to distinguish between AI/AN Tribes or Corporations, First Nations/Metis from Canada, and Indigenous Tribes from Mexico, Central and South America

Key Recommendations

- Request Tribal Consultation on developing policies for allowing appropriate access to disaggregated data on individual Tribal Nations
- Request federal agencies develop replicable methods, tools, and datasets for population estimates at multiple geographic levels
- Recommend OMB work across agencies to ensure federal efforts are aligned and coordinated in meeting the needs of Al/AN communities

Final Thoughts

- Tribes and urban Indian communities urgently need accurate and actionable data to improve their communities' health
- There likely is no single solution that will address the multiple challenges related to data collection and reporting for AI/AN communities
- Including Tribal input on data collection and release policies and the design of data collection systems is a starting point for improving the usability state and federal data for Tribes

Acknowledgements and Contact



- Tribes of Idaho, Oregon, and Washington leaders, delegates, patients, and families
- Indian Health Service, state health departments, and other partners
- Funders at IHS, CDC, and other agencies

Contact: sjoshi@npaihb.org



RESULTS FROM THE
NATIONAL TRIBAL HEALTH
CONFERENCE ROUNDTABLE
ON RACE AND ETHNICITY
STANDARDS

National Indian Health Board Rochelle Ruffer, PhD
National Indian Health Board
Tribal Health Data Project Director



BACKGROUND

- BCBSA Roundtable: "Setting Standards for Collection of Race Data in Healthcare Settings to Support Tribal Health Equity"
- National Tribal Health Conference in Anchorage, AK Tuesday, May 2, 2023
- 125 roundtable participants shared their perspectives on how the healthcare industry should approach race and ethnicity data collection to best support Tribes, Tribal sovereignty, and Tribal health equity





CONSIDERING DIFFERENT OPTIONS FOR HOW THESE QUESTIONS COULD BE PRESENTED

OMB Proposed definition of Al/AN: "All individuals who identify with any of the original peoples of North, Central, and South America."

Option for separating race question from Tribal affiliation

QUESTIONS THAT TOUCH IDENTITY ARE COMPLEX AND DEEPLY PERSONAL

"What keeps us alive, what keeps us here: it's identity, relation. It's the earth. It's each other."

"I think it's great having these conversations, but obviously these are very complicated issues."

"That makes no sense why we constantly have to justify who we are and what box we fit in."



TAKE-AWAYS

What did we learn?

WHAT IS THIS DATA REALLY FOR?

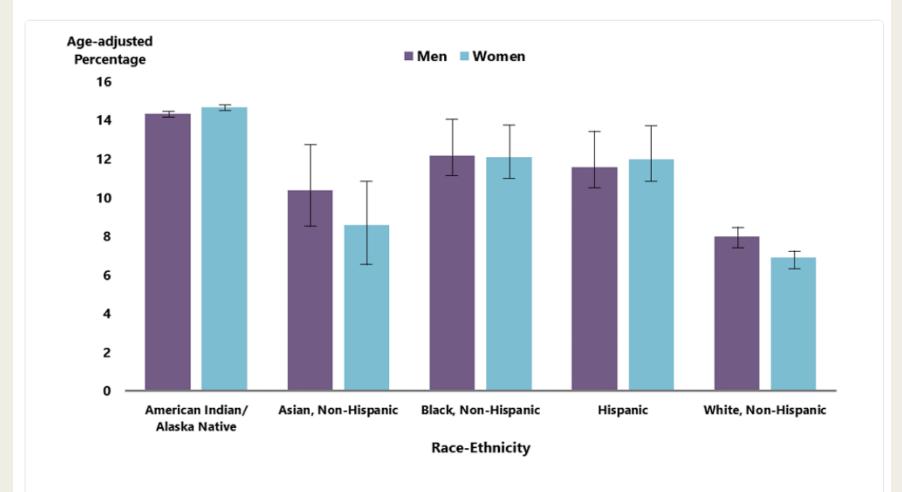
"Race" as a Proxy Variable



"WHAT'S THE INTENT BEHIND ASKING THOSE QUESTIONS [ABOUT RACE OR TRIBAL AFFILIATION]? THAT'S IMPORTANT TO KNOW AS WE'RE TRYING TO MAKE RECOMMENDATIONS HERE."

"RACE" AS A PROXY FOR "RACISM"

Figure 2. Age-adjusted estimated prevalence of diagnosed diabetes by race/ethnicity group and sex for adults aged 18 years or older, United States, 2018–2019



Note: Error bars represent upper and lower bounds of the 95% confidence interval.

Data sources: 2018–2019 National Health Interview Survey; 2019 Indian Health Service National Data Warehouse (for American Indian/Alaska Native group only).

"RACE" AS A PROXY FOR "RACISM"

- "As a Native person who does not appear native, people don't look at me and think I'm American Indian. But race is trying to get at that **phenotype**. What do you look like, and **how does that impact how people treat you in the world**?"
- "When you think about people who are doing ancestry.com, and so say they are told by this database that they have American Indian, Alaskan Native, or Indigenous heritage, although it doesn't include necessarily a Tribe, that indicator may prompt someone to answer this question, and what does that do? Because from a Tribal perspective, what we're looking at are the social determinants and the demographics that impact, say, chronic disease rates in our communities. And we want to gather the information that surround that dynamic. And if you have someone who is dissociated from that for whatever colonialized reasons, it may skew the data to some degree."

WHEN THE GOAL IS UNDERSTANDING THE IMPACT OF RACISM, SHOULD ALL INDIGENOUS PEOPLE BE COUNTED?

- "Working in an urban space on the East Coast, I [preferred the more inclusive option] because of the diversity of local city populations. In a place like Rhode Island where there are many thousands of Tribal peoples who are not eligible for enrollment... and this is because they've endured many centuries of colonization as a first contact people and have been greatly written out of history by all of our states in those areas and also de-tribalized formally... So I think that we do have to find a way to capture folks who have this diverse ancestry. And we have a lot of folks from Canadian First Nations in the Northeast... and I think this is true in a lot of urban areas where there's a tremendous Caribbean, South and Central American population who identify strongly as Indigenous peoples. They speak their languages. We see each other at the same kinds of cultural events, but we also recognize these vast differences in our indigeneity based on our ancestral experiences with colonization."
- "We talked a lot about just saying "Indigenous," because it opens the spectrum to a lot of Indigenous peoples. And so because we are a nation of mixed ethnicities, that opens it up so that we're not having to do these sub-limits... We don't want to limit ourselves."

"RACE" AS A PROXY FOR POLITICAL STATUS

- "When it comes to our people, we have a trust obligation that we rely upon. We have political status. We have Tribal Sovereignty. And when folks are talking about American Indians and Alaskan Natives, they need to be talking about it in that parlance."
- "Why are we asking about the South Americans and First Nation people, when the Federal Government has a trust responsibility to the Native people here in the United States?"
- · "Race is trying to get at that phenotype… But we also need a [separate] question about the political status."
- "[I would want to] add a second part to that question to make sure I'm also counting citizenship and membership specifically so that I can measure those who are obligated to services from IHS, if IHS is actually fulfilling their obligation to Tribal members who have that obligation."

THE POLITICAL STATUS OF "AI/AN" IS CONNECTED TO SPECIFIC, HARD-WON RIGHTS

- "I do not like the term "American Indian," but I also recognize that many of our foundational policy victories from our parents' generation, American Indian Religious Freedom Act, et cetera, et cetera, those use that same terminology. So I'm okay with it in terms of that racial category, because I recognize that as a citizen of the Standing Rock Sioux Nation that I have the right to assert my dual citizenship. So I don't mind being racialized in this category as long as I can foreground my citizenship."
- "Federally enrolled, that means something... It's the reason why Tribal members still exist."
- "We have to remember ... [that Tribes] had to fight major legal battles in order to get their federal recognition back, and they have. And so to discount those people is really not a good thing."

WHAT IF WE WANT TO TELL THE STORY OF HEALTH OF OUR WHOLE COMMUNITY?

- "As an epidemiologist, I think I would want to know the answer to [the Tribal affiliation question] as a whole, as citizenship, membership, affiliation, or community attachment."
- "I think what we're trying to get to is descendant. That's the word, right? We're talking about people who are citizens, members of the Tribe, or descendants, right, of an American Indian/Alaskan Native Tribe. We're talking about people that actually have a biological connection right to the Tribe."
- "We have non-Natives that grow up in Native communities... are they part of the community? Do they need to be counted as American Indian? Or as having community attachment?"

THE "RIGHT" QUESTION DEPENDS ON WHAT WE ARE REALLY TRYING TO MEASURE

WHAT IS THE RISK OF HARM?

Ethics, Accountability, and Sovereignty

ETHICS, TRUST, AND POTENTIAL DATA MISUSE

- "Mistakes on how data is gathered can be extremely harmful to Native peoples."
- "I've heard a lot of good comments about ethics. I think that's one of the biggest concerns about data being withheld from Tribes and held against us."
- "Well, tell us what you want," and we tell them, thinking they're going to take it wholeheartedly with good ethics and good mindset...And I often feel like when we get into these sessions, there are really good ideas, but that person that had that really good idea will retire. And five years, now all of a sudden we're starting with someone brand-new who said, 'No, that's not what it meant. It never meant that. It meant this."

DATA SOVEREIGNTY & AVOIDING UNINTENTIONAL HARM

"Tribal leaders need to decide if they want to collect that information about political status. As someone who would love to use this in the work that we do, I think it would be amazing, but I also think we need to acknowledge that there might be hesitancy to include that by Tribal leaders for a lot of reasons, not the least of which is that it could be weaponized against them. And so if that were to be included, there has to be some sort of acknowledgement of that and some sort of protections that this won't be used to harm Native people in some way or used to get-so again, what if we had a dashboard run by the Federal Government that lists every Tribe by their obesity rates, right? If you collect Tribal affiliation, you could do that. And as a Tribal leader, I could see being like, "Well, I'm not sure I want you guys to collect that information on my people if you're going to do something like that." So if this [question about Tribal membership] was to be included, there has to be protections."

"[With the option] to identify a Tribe in there, that runs the risk... of creating a Tribal registry that's not under Tribal sovereignty... I anticipate that that would be not something everybody would be okay with. And I was concerned. Now I'm an epidemiologist, and if I had no ethics or morals, I would love to have that data [and not worry about] how I get it, but that's not the world I live in."

"THE OFFICE OF MANAGEMENT AND BUDGET IS GOING TO DO THIS WHETHER WE PARTICIPATE OR NOT, AND THEY'RE GOING TO CREATE STANDARDS THAT WILL BE USED BY EVERY AGENCY OF THE FEDERAL GOVERNMENT TO COLLECT DATA, AND THEY WILL TELL A STORY BASED ON THAT DATA. AND WE NEED TO HELP THE AUTHORSHIP OF THAT DATA AND TO SET THE COURSE FOR THAT RIVER SO IT DOES NOT FLOOD OUR VILLAGES."

WILL THIS BENEFIT TRIBES?



- "Then I would also say there has to be some guarantee that that information is getting back to the Tribe, because the reason to include [Tribal affiliation] is so that I know in my community what the rates of diabetes are better than I do now. But if you just collect it and put it on a dashboard and then never tell me, I might not want that question."
- "If you are the epidemiologist that's getting this data or you're the Tribe that wants this data, you really want the most granularity in that data so that you can do what you need with that data and that's most applicable to your Tribe or your community. And so a category that offers as much granularity in that data is probably going to be the best option."

"THERE'S A NARRATIVE HERE THAT'S BEING BUILT, AND WE WERE NEVER BROUGHT INTO THE CONVERSATION OF HOW WE WANT TO CREATE THAT NARRATIVE TO DESCRIBE OURSELF, TO DESCRIBE OUR COMMUNITIES. WE SHOULD HAVE HAD INPUT IN THAT FIRST PLACE. LIKE WE WERE TALKING ABOUT, WHAT'S THE INTENT BEHIND THIS? WE DON'T KNOW. WE DON'T KNOW THE FULL PICTURE YET. SO WHY ARE WE EXPECTED TO ANSWER THESE QUESTIONS, GIVE OUR OPINIONS, WHEN WE DON'T KNOW HOW THIS IS GOING TO IMPACT OUR COMMUNITIES?"

HOW WILL IT BE OPERATIONALIZED?

Practical Considerations

HOW WILL THE DATA BE CAPTURED?

- "Making sure how it's operationalized. So it's how are we asking it, and how would it be interpreted? How is it operationalized with the other race/ethnicity variables?"
- "I'm thinking if they choose to do Tribal affiliation, they really should have a dropdown menu linked to the 576 federally recognized Tribes, only because you think they can read everybody's handwriting? Really? And what if the person only writes in their language? What are they going to do with those? Throw them out? Not count them? I can just see it being a disaster."
- "I am enrolled in Fort Peck under Sioux, but I'm also Chippewa Cree. So which do I go through?"
- "It's really not being discussed here, which is **the clan-ship system that's unique to the Tribes**, and they hold it dear."
- "It's how are we asking the question about Tribal affiliation... making sure it's really clear to the person who's answering it that we want to list all Tribal affiliations, right? So we want to capture that richness, that complexity of that information. So how the question is phrased and then how the respondent will fill it out is really, really important so that we're getting the right information."
- "We liked the idea that you can select multiple race/ethnicity and make sure that you're putting all of your affiliations in there."

HOW WILL THE DATA BE SORTED, ANALYZED, AND REPORTED?

- "How is this information then accessed, analyzed, and disseminated? So there's multiple layers to this question."
- "As far as just how the data from that particular subcategory option is being taken, like electronic or on paper and that kind of thing, how that transitions into the data that we see as far as numbers."
- "These two options really leave out a category that's important when you're looking at mixed ethnicity, mixed race, mixed heritage. And often times people are not going to be wanting to choose one or the other, and so they may not even answer it. Or if they answer in two categories, typically that data gets lost and doesn't even get counted."
- "If you pick other nationalities or whatever, it is kicked out. It's not counted."
- "[Sometimes mixed-race Caucasian and Al/AN] will be counted as Caucasian, though. But why? I always wondered why. So we have Caucasians, but we're the Indigenous people. Why doesn't it kick back to us instead of going to a white man and counting towards them? We were here first. This is our land, and it really should kick back to an Indigenous factor."
 National Indian Health Board



SUMMARY OF MAJOR THEMES

- No consensus on terminology to use or standards for inclusion/exclusion
- Concerns around the intended purpose of the data
- Distrust & concerns around data misuse, data security
- Concerns around Tribal data sovereignty
- Concerns around implementing standards in a way that will be practical and effective

RECOMMENDATIONS

- Collecting more data requires enacting more protections against the weaponization of the data collected and to uphold Tribal data sovereignty.
- Need to be clear about the intent and reason for collecting the data.
- There is a need for building trust.
- Improve on communicating the reasons for the data collection.
- Improve guidance on how people will be represented in the data if they select multiple races/ethnicities and/or Tribes/Corporations.
 National Indian Health Board





Roundtable: Promising Practices to Improve How Race & Ethnicity Data Are Used in Public Health, Healthcare, and Research- Current Strategies for Improvement through an Intergenerational Lens

Delight Satter, MPH
(Confederated Tribes of Grand Ronde)
Senior Health Scientist
Office of the Director
CDC

National Indian Health Board
Tribal Health Equity Data Symposium
September 25-6, 2023





Data on American Indians & Alaska Natives Are Hard to Access

Nearly 6 million American Indians and Alaska Natives (AIAN) live in the United States. However, it is hard to uncover AIAN data in population health surveys because of the limited accessibility of AIAN information in these datasets.

AIAN make up 1.7% of the U.S. population

AIAN 5.7 population in the U.S. million

Total U.S population

330 million

Source: 2019 American Community Survey, American Indian and Alaska Native alone or in combination with one or more race



"Federal health surveys provide nationally representative estimates for the U.S. population, but insights on Native populations are limited because of the small number of Native respondents in probability-based sampling frames and non-collection of tribal affiliation. The small sample size leads to data suppression and aggregation of data and racial/ethnic identity tabulation rules that inaccurately capture the Native population - many of whom are multiracial and also identify as Latinx/Hispanic."

-Ninez Ponce, Professor of Health Policy & Management & Director, UCLA Center for Health Policy Research, UCLA, Fielding School of Public Health

Current Strategies for Improvement and Correction

- Oversampling
- Release pooled multi-year public use files
- Include information to identify the overall AIAN population
- Reduce cost/time for accessing restricted data
- Report on how race/ethnicity is defined in your study
- Note when conclusions about AIAN health are based solely on singlerace non-Latinx AIANs

Improving Data Capacity for American Indian/Alaska Native Populations in Federal Health Surveys

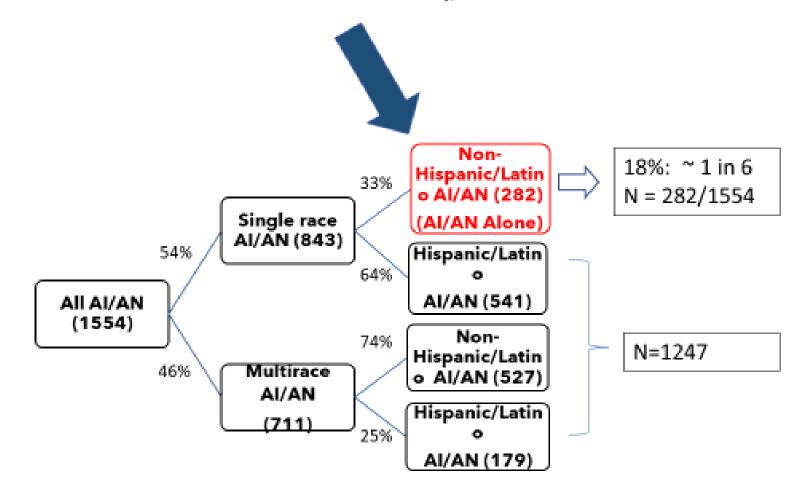
- Key messages:
 - Among the subgroups with the highest rates of poor health outcomes is the American Indian/Alaska Native (AIAN) population, which is also at significant risk of misidentification in national surveillance instruments.
 - This report demonstrates that classification and weighting decisions affect the measurement of the
 population characteristics and health outcomes for the AIAN population. We share observations
 that can inform data production and processing efforts in major health surveys to advance the
 insights on the AIAN population. Increasing data capacity for the AIAN population will improve the
 knowledge about the health of specific subgroups within the AIAN population, and better guide
 allocation of public health resources.

Source: Al AN Data Capacity | ASPE (hhs.gov)

The Assistant Secretary for Planning and Evaluation

Implications for Coding Race and Ethnicity for American Indian and Alaska Native High School Students in a National Survey

American Indian or Alaska Native (AI/AN) Racial/Ethnic Classifications
National Youth Risk Behavior Survey, 2017 and 2019



Recommendations from the National Commission to Transform Public Health Data Systems: AIAN Expert Panel

- Each panel consisted of individuals who brought expertise to the issues based both on their work and training with data and their own lived experience.
- Having the expertise and voices from those communities was critical to shaping recommended strategies and approaches to advance data systems and data equity.
- All panels highlighted the importance of
 - narrative change around health, well-being, and equity;
 - the need to decolonize and disaggregate data;
 - the importance of authentic community engagement in data decision-making;
 - the importance of training and capacity-building around data;
 - and the need to overlap intersectional identities and experiences in more comprehensive data systems.

Charting a Course for an Equity-Centered Data System:

Recommendations from the National Commission to Transform Public Health Data Systems

OCTOBER 2021



The National Commission to Transform
Public Health Data Systems was convened by
The Robert Wood Johnson Foundation.

Recommendations from the National Commission to Transform Public Health Data Systems (continued)

"Data speaks, it sings, it carves, it paints. And how we tell the story is very powerful." Commissioner Abigail Echo-Hawk

FIGURE 1. TRHT FRAMEWORK Narrative Change Racial Healing and Relationship Building Separation Economy Law (Segregation & (Civil, Criminal & (Structured Inequality & Barriers Concentrated **Public Policies**) Poverty) to Opportunity)

Recommendations from the National Commission to Transform Public Health Data Systems (continued)

CALL TO ACTION SUMMARY

Government as well as private and other civil society sectors have a role to play in transforming our public health data system.

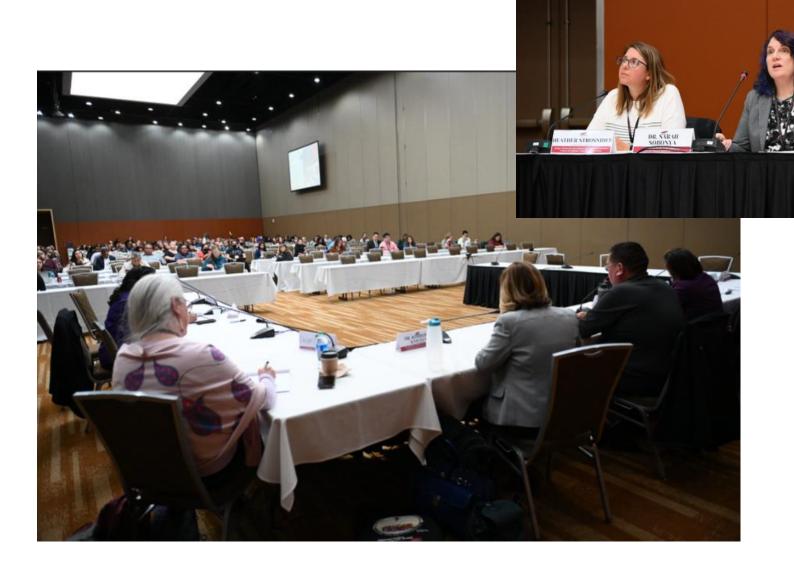
SECTOR

ACTION

FEDERAL GOVERNMENT

- Develop minimum standards about data collection, disaggregation, presentation, and access, in federally funded data collection efforts, with an orientation to "freeing federal data" or promoting greater access.
- Strengthen public health data infrastructure and incentivize the use of new data collection and analytic approaches.
- Federal funding for data infrastructure should be prioritized to systems that are standardsbased and interoperable.
- Offer guidance on interpretation of racial/ethnic variation in health-relevant data to counter longstanding acceptance of the idea that these variations reflect biological differences rather than systemic, cultural, behavioral, and social factors.

CDC/ATSDR Listening Session on Tribal Health Data Modernization Initiative



National Tribal Health Conference, National Indian Health Board, Anchorage Alaska, May 2023. Images courtesy of NIHB.

For more information visit, <u>Data</u> <u>Modernization Initiative | CDC</u>

Supporting Tribal Data Modernization

CDC's Office of Public Health Data, Surveillance, and Technology



Overview

- Data Modernization Overview
- Tribal Data Modernization Projects
- Electronic Case Reporting (eCR) for Tribal Public Health

WHAT IS THE

Data Modernization Initiative?

A national effort to create modern, integrated, and real-time public health data and surveillance that can protect us from any health threat.

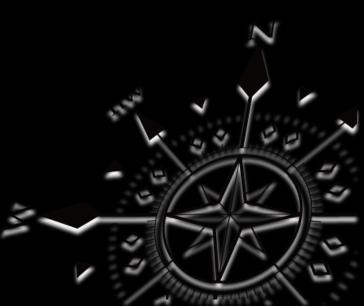




Our Ultimate Goal

To move from siloed and brittle public health data systems to connected, resilient, adaptable, and sustainable 'response-ready' systems that can help us solve problems before they happen and reduce the harm caused by the problems that do happen.

Better, Faster, Actionable Insights for Decision-Making



Tribal Data Modernization Project Funding

CDC is supporting data modernization efforts with tribal public health and healthcare partners. Initial funding of 3 partners totaling \$750,000 in 2020 has grown to funding of six partners totaling \$2,989,000 in 2021 and nine partners totaling \$4,076,245 in 2022.

Accelerating Public Health Data
Modernization in Tribal Jurisdictions

Funded Entities:

- Alaska Native Tribal Health Consortium
- Rocky Mountain Tribal Leaders Council
- Northwest Portland Area Indian Health Board
- Wabanaki Public Health and Wellness

2022 Total Funding: \$1,301,245



Tribal Data Modernization

- Focused Investments

Funded Entities:

- Chickasaw Nation
- Great Lakes Intertribal Council
- Northwest Portland Area Indian Health Board
- Southern Plains Tribal Health Board
- Wabanaki Public Health and Wellness

2022 Total Funding: \$1,250,000



Data Modernization in Tribal Jurisdictions

Funded Entities:

- Alaska Native Tribal Health Consortium
- Wabanaki Public Health and Wellness
- Northwest Portland Area Indian Health Board
- Rocky Mountain Tribal Leaders Council
- Chickasaw Nation
- Great Lakes Intertribal Council

2023 Total Funding: \$3,499,917



Key Data Modernization Activities

Focus Area

		Focus Area				
		Assessment	Governance	Data Integration	Infrastructure	Analytics
	ANTHC			Improved representation of Tribal groups within vaccination data	Developed Population Health Management Immunization Dashboard	Established automated processes for preparing raw data for analysis
	RMTLC	Conducted data assessment and identified gaps in data exchange	Created agreements to improve health information systems			Data visualization trainings
rarrner	NIHB			Automated real-time exchange of case reports	Streamlined Electronic Case Reporting (eCR)	
	Wabanaki	Compiled data into Wabanaki PH Surveillance System	Established data sharing agreements		Employ cloud technology for data lakes	Data analytic and visualization trainings
	NPAIHB	Assessed training needs for Northwest TEC	Established Advisory Committee for data asset assessment	Developed and implemented enhanced protocols and datasharing agreements		Data visualization trainings
	Chickasaw	Develop data assessment and strategy	Develop Tribal Consortium Data Subcommittee			
	GLITC				IT improvements addressing gaps/needs	
	SPTHB	Conduct data capacity assessment and develop workplans				

Reflections and Acknowledgements







For more information, contact CDC

1-800-CDC-INFO (232-4636)

TTY: 1-888-232-6348. | www.cdc.gov

Masi! Thank you!

Delight Satter, zuc0@cdc.gov