



UNDERCOUNTED AND UNDERSERVED

HOW FLAWED DATA REPORTING HURTS TRIBAL HEALTHCARE

In healthcare, we toss around the terms underserved and underrepresented on a regular basis. To most of us, they're shorthand for unfairness and deprivation. But at their heart, these are mathematical terms that indicate a simple equation: a group of people is receiving fewer resources than their numbers merit. That's the case with Native American communities. For a number of reasons, their data – from hospitalization numbers to census results to racial classification at death – is consistently skewed.

These errors have serious, far-reaching ramifications in healthcare, such as decreased funding, lack of clinical and policy representation, and an inability to solve healthcare disparities. We can't address what we can't see, after all. Tribal leaders can't shape community development initiatives without current information; epidemiologists can't design pre-emptive strategies for future pandemics without an accurate report of this one. Healthcare leaders can't devise effective outreach strategies, fund vaccine allocations, and measure success or failure in their healthcare systems. Worst of all, blurred data on Native people makes it easier for the federal government to sidestep obligations and fail to honor treaties.

The Pervasive Problem of Racial Misclassification

Studies turn up a range of disquieting results when it comes to Native Americans and racial classification. One study found a 50% chance of being listed as the wrong race on medical records, and birth and death certificates. [A 2015 study of hospital discharge records in Oregon](#) found that over half of Native patients had been miscategorized on their file, with most listed as white. [A 2016 report](#) from the National Center for Health Statistics concluded that of everyone who self-identified as American Indian or Alaska Native on the U.S. Census, 48.6 percent were classified as another race on their death certificate.

In an age where healthcare leaders rely on data to solve population health challenges, accurate race and ethnic data is crucial. Those numbers help payers, hospital networks, public health leaders, and federal agencies design targeted outreach campaigns, assess language preferences, and plan for culturally informed care delivery.

Fortunately, this is also the age of next-generation technology that can extract, categorize, and translate mass quantities of raw data into actionable insights. So why is population and healthcare data on Native Americans so murky?

Ambiguity, Mistrust, and Being an “Other”

If you pay attention to Indigenous news, you might have spotted a positive recent update. After [multiple outreach campaigns](#) fighting for an [accurate Census tally](#), the number of people who identified as [Native American and Alaska Native \(AIAN\)](#) alone and in combination with another race is now 9.7 million, up from 5.2 million in 2010.

That’s a big jump – but Tribal advocates think this is still an undercount. Here are a few reasons why this recent data probably isn’t accurate:

- 1. Fear of discrimination.** Patients and health plan members who’ve experienced discrimination in clinical settings may hesitate to identify their race in future healthcare encounters. Whether they’re selecting a health plan, completing an intake form, or speaking to a clinician, they may worry that identifying as Native American might create bias or reduce their care options.
- 2. Mistrust of Census workers.** The COVID-19 pandemic limited options for Tribal members to train as Census workers – and some Tribal leaders think the drop in Indigenous Census workers increased government mistrust and made some Tribal members reluctant to respond to the survey.
- 3. Difficulty being reached for census data.** Many residents living on Tribal lands and reservations have addresses that aren’t listed; they often lack Internet access as well. They never come into contact with a Census taker, relying on materials dropped at their front doors. If they don’t receive the materials, they aren’t counted in the Census.
- 4. Being listed as “Other.”** Because Native American numbers are small compared to other racial and ethnic groups, some states and institutions categorize them as “other.” A Guardian analysis found that almost half of the state health departments who released racial demographic data on COVID [omitted Native Americans in their report](#), grouping them with everyone else in the “Other” category. This casual erasure happens across disciplines; when the CDC released a study on race and maternal mortality rates, Native Americans were again omitted. Yet the Urban Indian Health Institute found Native women living in cities were 4.5 times more likely to die during pregnancy and childbirth than white women – a story worth telling, yet one ignored by the nation’s top health protection agency.



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of Native Americans are classified as another race on their death certificate.

5. **The complex ambiguity of racial and ethnic identity.** The United States Census Bureau [has five categories](#) for race: Black/African American, American Indian/Alaska Native, Asian, Native Hawaiian/Pacific Islander, and White. Only beginning in 2010 were respondents allowed to choose multiple races. Many hospital forms, software systems, and surveys offer rigid categories, leaving some patients unsure which box to check. Patients may feel forced to make an arbitrary choice; hospital workers and government staff may guess at a patient's background. But these simple categories erase many Indigenous people's rich heritage. Consider that [Latinos now make up nearly 31% of the total Native population](#), according to the Census Bureau; about 61%, or 5.9 million, of those who identified as American Indian and Alaska Native population last year are multiracial.

Multiracial Erasure

- ▶ 61% of Native Americans are multiracial.
- ▶ Latinos make up nearly 31% of the total Native population.
- ▶ The number of Americans who identify with multiple racial groups increased 300% in the last census.

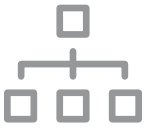


The Cloud Around COVID-19 Data

By now, most everyone understands the COVID-19 pandemic has hit Native Americans with [dramatically disproportionate rates of infection and death](#). Tribal communities bear the [highest death rate of any ethnic group](#) in the United States. Arizona's department of health services [reported](#) that Native Americans make up 16% of the state's COVID-19 deaths, despite representing only 6% of the population; [New Mexico found](#) Native Americans make up over one-third of coronavirus cases despite constituting less than 10% of the population.

But once again, even these frightening numbers are likely an undercount. A 2021 [Urban Indian Health Institute report card](#) gives most states a C grade or lower when it comes to collecting and reporting accurate COVID-19 data for Indigenous people. Even when Native Americans are counted, it tends to be in one big data set. That doesn't tell Tribal governments how the virus has impacted their citizens – information that counties and states regularly receive about their citizens.

For multiple reasons, a cloud of data confusion masks the [extent of the Native American COVID crisis](#):



Lack of a centralized data repository: There's no digital thread tracking Indigenous COVID-19 patients across every IHS health facility, Tribal facility, urban Native health program, and city, county, and private hospital. Local, state, federal and Tribal reporting systems don't always share data with each other. Because the majority of IHS facilities do not provide intensive care, many critically ill patients are transferred to non-IHS hospitals – who may not report the death back to IHS. And so it becomes difficult to track hospitalization or mortality data for Indigenous patients.



Inability to access death data: Tribal advocates [have requested public records](#) from state medical examiners in Colorado, New Mexico, Arizona and Utah – but data custodians denied those requests, citing privacy concerns. Knowing the date, race, gender, ethnicity, cause and location of death, age, and COVID-related information would help Tribal leaders understand who died from their communities and how – but those death details remain obscured.



Misidentification of race and ethnicity: Consider the variety of data collection practices in hospitals, country morgues, and funeral homes. In some, a funeral director may fill out vital statistics forms with the deceased's family members, who are the most likely to provide the correct ethnicity. But in many places, it's common practice for medical staff, coroners, or funeral home directors to look at the patient and make their best guess. In an [increasingly multiracial nation](#), this is bound to camouflage the patient's full identity.

Aligning Data Collection with Native American Identity

Native Americans are not "Other." They may constitute a small percentage of the American population, but they are entitled to the same recognition, dignity, and attention as any other group. Omission is a silent harm that erases Indigenous people's needs and experiences.

Is there a simple way to ensure the collection of timely and correct data? Not right away – but at a [2020 COVID-19 response hearing](#), IHS Chief Medical Officer Rear Admiral Michael Toedt testified that IHS is working with the CDC to implement training to correct racial misclassification. Other helpful measures include improving death certificate completion methodology, including Native Americans in demographic data, and including Tribal affiliation in reporting. As our nation becomes increasingly multiracial – the number of people who identify with multiple racial groups increased 300% in the last census – all data collection needs to be structured for the complexity of racial and ethnic identity.

True generational change begins with knowledge. From building healthcare resilience to repairing cultural ruptures, precise data on Native American experiences provides a roadmap to effective strategies. Changing Tribal communities from underserved to well served will take time – but we can start by counting accurately.