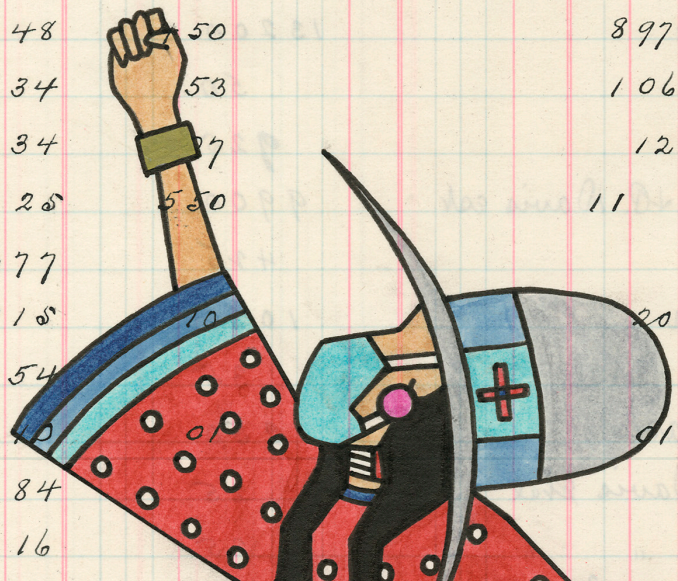


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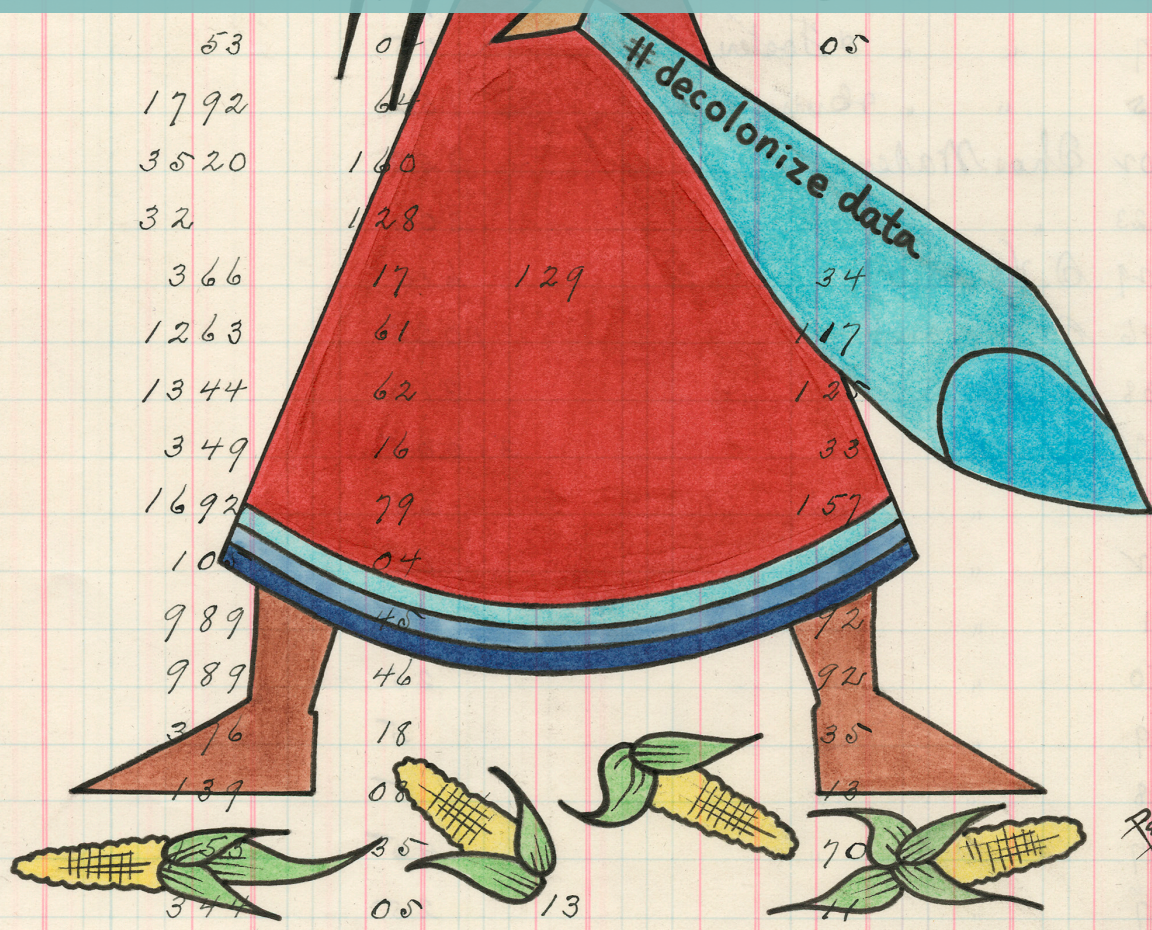
Urban Indian Health Institute
A Division of the Seattle Indian Health Board



Data Genocide of American Indians and Alaska Natives in COVID-19 Data

A report card grading U.S. States' quality of COVID-19 racial data and their effectiveness in collecting and reporting data on American Indian and Alaska Native populations

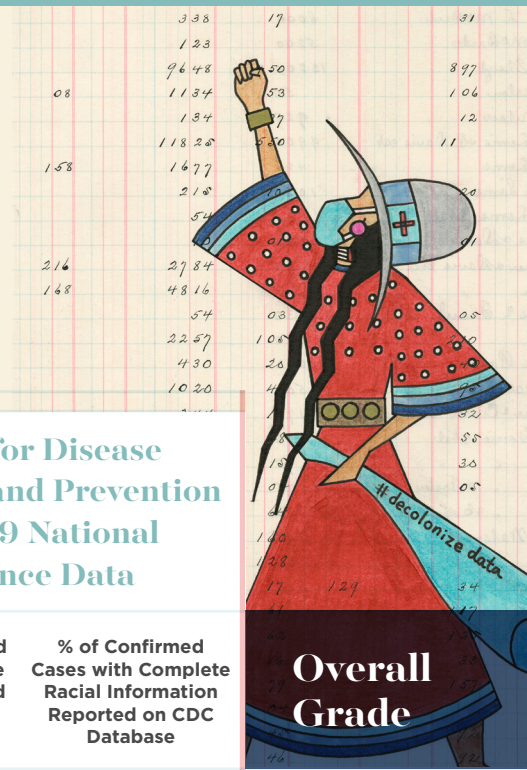
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	1344	62		125	2044
	349	16		33	479
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	10	04			128
09	989	45		72	1567
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	376	18		35	516
03	139	08		18	396
	344	05	13	70	1635
				11	453



Pepon

Report Card

Data Genocide of American Indians and Alaska Natives in COVID-19 Data



State Information		State Reported COVID-19 Information		Centers for Disease Control and Prevention COVID-19 National Surveillance Data		Overall Grade
State	American Indian/Alaska Native (AI/AN) Population*	Is AI/AN Population Included on State Dashboard	% of Cases with Complete Racial Information Reported on State Dashboard	% of Confirmed Cases from the State Reported to CDC	% of Confirmed Cases with Complete Racial Information Reported on CDC Database	
Alabama	69,283	No (0%)	F (49%)	D- (62%)	D- (62%)	F (43%)
Alaska	148,222	Yes (100%)	D- (62%)	—	F (59%)	C (74%)
Arizona	458,422	Yes (100%)	C- (72%)	A (95%)	D (63%)	B (83%)
Arkansas	61,824	Yes (100%)	B- (82%)	A (95%)	B (85%)	A- (91%)
California	1,089,251	Yes (100%)	D (65%)	A+ (99%)	F (37%)	C (75%)
Colorado	159,162	Yes (100%)	C (73%)	C (76%)	F (38%)	C- (72%)
Connecticut	43,195	Yes (100%)	F (53%)	B (84%)	F (40%)	D+ (69%)
Delaware	13,516	No (0%)	B+ (89%)	A (96%)	F (0%)	F (46%)
Florida	219,895	No (0%)	C (76%)	F (50%)	D (65%)	F (48%)
Georgia	122,051	Yes (100%)	C (76%)	C+ (77%)	F (43%)	C (74%)
Hawaii	37,751	No (0%)	D (65%)	B (83%)	F (50%)	F (49%)
Idaho	51,467	Yes (100%)	F (59%)	A- (92%)	F (59%)	C+ (77%)
Illinois	141,473	Yes (100%)	D+ (67%)	A- (92%)	F (52%)	C+ (78%)
Indiana	66,617	No (0%)	C (75%)	D (66%)	D- (61%)	F (50%)
Iowa	33,753	Yes (100%)	D (65%)	B+ (89%)	D+ (69%)	B- (81%)
Kansas	69,645	Yes (100%)	C+ (77%)	B- (82%)	C+ (78%)	B (84%)
Kentucky	38,568	No (0%)	C (74%)	F (40%)	B- (80%)	F (48%)
Louisiana	65,461	Yes (100%)	B (85%)	F (6%)	F (59%)	D (63%)
Maine	20,865	Yes (100%)	B (84%)	A (94%)	B (85%)	A- (91%)
Maryland	81,228	No (0%)	B- (81%)	F (41%)	F (35%)	F (39%)
Massachusetts	75,027	Yes (100%)	D+ (67%)	A+ (98%)	F (59%)	B- (81%)
Michigan	158,391	Yes (100%)	C- (70%)	F (59%)	B- (80%)	C+ (77%)

State Information		State Reported COVID-19 Information		Centers for Disease Control and Prevention COVID-19 National Surveillance Data		Overall Grade
State	American Indian/Alaska Native (AI/AN) Population*	Is AI/AN Population Included on State Dashboard	% of Cases with Complete Racial Information Reported on State Dashboard	% of Confirmed Cases from the State Reported to CDC	% of Confirmed Cases with Complete Racial Information Reported on CDC Database	
Minnesota	124,345	Yes (100%)	B+ (88%)	A+ (100%)	B (83%)	A (93%)
Mississippi	31,669	Yes (100%)	B (83%)	F (29%)	B (84%)	C (74%)
Missouri	87,760	Yes (100%)	D- (60%)	F (13%)	C- (70%)	D- (61%)
Montana	90,472	Yes (100%)	C- (70%)	A (96%)	C- (72%)	B (84%)
Nebraska	43,760	Yes (100%)	F (58%)	F (27%)	C+ (78%)	D (66%)
Nevada	85,953	Yes (100%)	B+ (87%)	B+ (89%)	F (53%)	B- (82%)
New Hampshire	12,534	No (0%)	F (57%)	F (20%)	B- (81%)	F (39%)
New Jersey	102,441	No (0%)	D (63%)	A+ (98%)	F (48%)	F (52%)
New Mexico	257,858	Yes (100%)	C (76%)	F (35%)	D (64%)	D+ (69%)
New York	318,858	No (0%)	F (0%)	D+ (69%)	F (39%)	F (27%)
North Carolina	245,724	Yes (100%)	C- (70%)	A+ (99%)	C- (70%)	B (85%)
North Dakota	51,664	Yes (100%)	D (63%)	F (50%)	F (6%)	F (55%)
Ohio	107,899	Yes (100%)	C- (70%)	—	C (73%)	B- (81%)
Oklahoma	553,509	Yes (100%)	C (74%)	B- (80%)	C+ (77%)	B (83%)
Oregon	146,851	Yes (100%)	F (56%)	A (94%)	F (57%)	C+ (77%)
Pennsylvania	117,073	No (0%)	F (59%)	A+ (99%)	D (63%)	F (55%)
Rhode Island	20,190	Yes (100%)	C (75%)	F (27%)	F (27%)	F (57%)
South Carolina	58,171	No (0%)	D (66%)	A+ (99%)	D+ (67%)	F (58%)
South Dakota	92,686	Yes (100%)	B+ (89%)	B (84%)	B (84%)	B+ (89%)
Tennessee	76,883	Yes (100%)	C (73%)	A+ (99%)	C- (71%)	B (86%)
Texas	485,363	No (0%)	F (3%)	F (3%)	C- (72%)	F (20%)
Utah	73,697	Yes (100%)	B (83%)	—	B- (82%)	B+ (88%)
Vermont	8,088	Yes (100%)	B+ (88%)	A- (92%)	A- (90%)	A (93%)
Virginia	109,216	Yes (100%)	C (74%)	B- (81%)	D (64%)	B- (80%)
Washington	264,596	Yes (100%)	F (54%)	A+ (100%)	F (43%)	C (74%)
West Virginia	15,137	No (0%)	D (64%)	F (8%)	A- (92%)	F (41%)
Wisconsin	106,202	Yes (100%)	B (86%)	B- (82%)	B+ (87%)	B+ (89%)
Wyoming	22,024	Yes (100%)	F (57%)	F (2%)	B (83%)	D- (61%)

State Information		State Reported COVID-19 Information		Centers for Disease Control and Prevention COVID-19 National Surveillance Data		Overall Grade
State	American Indian/Alaska Native (AI/AN) Population*	Is AI/AN Population Included on State Dashboard	% of Cases with Complete Racial Information Reported on State Dashboard	% of Confirmed Cases from the State Reported to CDC	% of Confirmed Cases with Complete Racial Information Reported on CDC Database	
United States Overall	6,935,690	C- (72%)	D+ (68%)	D+ (69%)	D (63%)	D+ (68%)

*AI/AN=American Indian/Alaska Native. AI/AN is defined as American Indian/Alaska Native only + American Indian/Alaska Native in combination.

*Population numbers are believed to be an undercount and should not be interpreted to represent tribal enrollment numbers.

— State reported a greater number of cases to CDC than reported on dashboard, therefore, we were unable to identify the percent of confirmed cases sent to the CDC.

Data Source for population: Population 2019 Postcensal estimates

Data source for state data: COVID Tracking Project

Data source for CDC data: CDC COVID-19 National Surveillance Data

Methodology:

Scores are based on the percentage of cases that meet each field or criteria.

Weight	Category
25%	AI/AN Included on State Dashboard
25%	% of Cases with Race Reported by state
25%	% of Cases Reported to CDC
25%	% of Cases with Race Reported to CDC

Grade	A+	A	A-	B+	B	B-	C+	C	C-	D+	D	D-	F
97-100	A+							73-76	C				
93-96		A						70-72	C-				
90-92			A-					67-69	D+				
87-89				B+				63-66	D				
83-86					B			60-62	D-				
80-82						B-		0-59	F				
77-79							C+						



Urban Indian Health Institute
A Division of the Seattle Indian Health Board

Our mission is to decolonize data, for Indigenous people, by Indigenous people.
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Introduction

The reporting of race and ethnicity in COVID-19 public health surveillance data has been woefully inadequate since the beginning of the pandemic in January 2020. Poor data collection and reporting standards implemented by states has resulted in a substantial gap in understanding the disproportionate impact of COVID-19 on people of color across the U.S., specifically American Indians and Alaska Natives (AI/AN). In Center for Disease Control and Prevention (CDC) Morbidity and Mortality Weekly Reports (MMWR), AI/AN communities have been shown to experience disproportionate morbidity and mortality due to the COVID-19 pandemic, with the rate of new infections and death among AI/AN people estimated to be 3.5 and 1.8 times that of non-Hispanic Whites, respectively.^{1,2} However, the MMWR report on COVID-19 infections notes the authors were only able to include 23 states in the analysis, as they were the only states that had collected at least 70% or more of race and ethnicity data.² The Council of State and Territorial Epidemiologists states, **“the value and quality of the nation’s public health surveillance system relies on efficient and accurate data flow from source to the agencies to make evidence-based decisions.”**³

As illustrated by the studies cited above, efficient and accurate data is not achievable with current systems of data collection and reporting. This lack of data obscures the true burden experienced by AI/AN communities and directly impacts the ability of local, state, federal, territorial, and tribal public health authorities to address the disproportionate impact of COVID-19 in their communities and limits policy makers’ ability to make data-driven decisions for equitable policy and adequate resource allocation.

As our relatives continue to die at disproportionate rates from COVID-19, they are not given the dignity of telling their final story as they are eliminated in the data.

—Abigail Echo-Hawk, UIHI

Structural racism

The normalization and legitimization of an array of dynamics (historical, cultural, institutional and interpersonal) that routinely advantage White people while producing cumulative and chronic adverse outcomes for people of color.

Source: Call to Action: Structural Racism as a Fundamental Driver of Health Disparities: A Presidential Advisory From the American Heart Association

Urban Indian Health Institute’s (UIHI) mission, as a Tribal Epidemiology Center, is the reclamation of the cultural value systems of data collection—for Indigenous people, by Indigenous people—to conduct research and evaluation with the central goal of ensuring the well-being of the community and a great future for the next generations. UIHI recognizes the systems of inequity that have inhibited representation of AI/AN in public health surveillance systems resulting in deficit-based data and invisibility through data erasure. This report specifically illustrates the **structural racism** embedded in data systems that

has led to the erasure of Indigenous peoples in data collection, analysis, and reporting. In *Ten Stages of American Indian Genocide*, the authors argue that “for almost 200 years under U.S. federal governance, there was a concerted effort to erase Native peoples... communities were exposed to extraordinary levels of violence and ever increasing levels of alienation, exclusion, and marginalization by the federal government.”⁴ The ongoing settler colonialism and genocidal practices are directly tied to acts of data genocide⁵ and data terrorism that is evidenced by being eliminated in the data and what scarce data is available being used to harm tribal nations and their citizens.⁶

In a recent decision, the U.S. Treasury based the allocation of CARES Act funds on Census Bureau data without the consultation of tribes, which resulted in the distribution of COVID-19 resources based on a negligent undercount of zero population or drastically reduced populations.⁷ Numerous tribes have taken legal actions against this as they continue to fight for basic resources and medical equipment during the pandemic.⁸ The drastic undercount of AI/AN in census data is well known, yet the federal government made a unilateral decision to use this data in determining the allocation of scarce resources in the midst of a devastating pandemic. This illustrates the ways in which data, or the lack thereof, has and continues to be weaponized against AI/AN communities.

UIHI recognizes that the scarcity of data on AI/AN is not by chance but rather a continuation of systemic and repeated attempts at elimination. The elimination of AI/AN people in data is not a new issue. Tribal leaders, Indigenous scholars, and allies have fought for decades for systematic change as they saw AI/AN relatives vanish in health surveillance systems ranging from chronic disease to cancer to vital statistics and more as a result of racial misclassification, non-collection of race and ethnicity, and use of

Tribal Sovereignty

Tribal sovereignty is the ability to govern and to protect and enhance the health, safety, and welfare of tribal citizens within tribal territory.

categories such as ‘other’ or ‘multi-race’ that do not allow for disaggregation.⁹⁻¹¹ These systems have been part of building and perpetuating health disparities as data and is directly tied to policy decisions and resource allocation. Very often the excuses as to why these issues continue are tied to lack of resources to overhaul data systems. However, it must be acknowledged that these systems were built to marginalize people of color and, specifically for AI/AN people, as a means for the federal government to falter on treaty obligations including access to quality

healthcare, which is paramount in this pandemic. Data has been used to intentionally eliminate, harm, or terrorize AI/AN communities for political, ideological, and social gain.⁶ There are documented instances of its use to withhold lifesaving resources, infringe on **tribal sovereignty**,¹² and enact racist policies.^{13,14} “American Indian genocide continues in this country,”⁴ and eliminating AI/AN in the data is part of the purposeful erasure.

Purpose

This Report Card on COVID-19 data quality provides insights into the shortcomings of the public health surveillance systems nationally in the collection of race and ethnicity data for COVID-19—despite the federal requirements for collection¹⁵—and urges state and federal actions to respond to this long-standing crisis we are facing in our public health data systems.

What are the current issues with COVID-19 surveillance and race?

On September 16, 2020, the CDC reported 50% of all COVID-19 cases were missing race and ethnicity data, with some states, such as New York, reporting no racial data on their state dashboard.¹⁸ Months later, the collection of race and ethnicity data has only improved marginally. As of February 10, 2021, the CDC reported 49% of COVID-19 cases were missing race and ethnicity with incomplete racial data ranging from 13-92% depending on health jurisdiction.¹⁹

This lack of racial data is also reflected in vaccine data. A recent study found 48% of race and ethnicity was missing for COVID-19 vaccination data, illustrating the pervasiveness of this issue.²⁰ The complete collection and reporting of race and ethnicity is essential in understanding how COVID-19 disproportionately impacts different populations, particularly those who have been historically marginalized by systems of structural and institutional racism.

What is public health surveillance?

Public health surveillance is the regular, timely collection, analysis, use, and sharing of data to inform public health activities that prevent and control disease.¹⁶ A core responsibility of state and federal governments is to protect the public's health and safety through measures like public health surveillance.¹⁷ Underlying the quality of public health activities, and subsequently the health of communities, is the quality of data.

Equity will not be achieved in COVID-19 response or vaccinations until public health surveillance systems properly collect and report race and ethnicity.

—Abigail Echo-Hawk, UIHI

How does poor racial data impact AI/AN communities?

Lack of quality data continues to misrepresent and obscure the burden of disease among AI/AN and other people of color, and health disparities can widen as a result of misinformed “data-driven” policies and programs, in addition to inadequate resource allocation. Several of the health implications of poor racial data include:

- omission and erasure of AI/AN in reports, publications, and literature.
- underestimation of the true severity of morbidity and mortality.
- inadequate public health programs and activities that are non-responsive to AI/AN communities.
- inequitable allocation of resources for disproportionately impacted communities.
- incorrect and limited understanding of racial health disparities.
- perpetuation of health disparities due to misinformed policies, programs, and insufficient resource allocation.

Who is accountable for poor racial data quality?

The U.S. public health system continues to be chronically underfunded and highly decentralized, which leads to a lack of integrated data systems and standardized data collection and reporting processes. Due to this, the reporting of COVID-19 cases varies by state. In general, with some exceptions, data flows from the point of collection (e.g., hospital, clinic, laboratory) to the local health district and then to the state who reports to the CDC.²¹ As discussed above, COVID-19 vaccination data is missing 48.1% of race and ethnicity data despite CDC required collection.^{20,22} While all stakeholders play a role in guaranteeing the quality of racial COVID-19 data, policymakers, state, and federal government agencies have the most power to enact and enforce data quality policies and standards.

Flow of data to CDC



Report card findings

Overall, the U.S. scores a failing grade of D+ for collection and reporting of AI/AN data across the four categories, demonstrating the impact of the data genocide of Native people. Sixteen states scored an F grade, the poorest grade coming from Texas with a cumulative score of 20% followed by New York (27%), Maryland (39%), New Hampshire (39%) and West Virginia (41%), respectively. More than half of states scored a C or lower including states with large populations of urban and rural AI/AN people including California (C) and New Mexico (D+).

No state scored an A+. However, two states, Minnesota and Vermont, both scored the highest overall grade of A (93%), closely followed by Maine and Arkansas with scores of A- (91%). Wisconsin and South Dakota followed with a B+ (89%), however North Dakota scored an F (55%), highlighting the variability in reporting state-to-state despite sharing a border. Eighteen states scored between a C+ and B+ including Arizona and Oklahoma, states with large AI/AN populations (458,422 and 553,509), who received a B grade.

These findings highlight the level of invisibility and erasure that AI/AN people are experiencing in the COVID-19 case data, and previous research shows us that also applies to other types of public health surveillance.⁹⁻¹¹ Yet, there are examples of successful reporting in states such as Minnesota and Vermont, illustrating that with concerted effort and resources, undoing the impact of colonial data systems that are making AI/AN people invisible is achievable.

Recommendations for collecting and reporting race/ethnicity²³

Data is a story, and storytelling has always been an integral part of Indigenous culture and knowledge systems. AI/AN people deserve the dignity and respect of having their stories represented in the data to be used for improving the health and wellbeing of their communities and the next generations. These recommendations work to ensure our people are not erased in the data and offer tools to fight against the data genocide of AI/AN people.

Mandate the collection and reporting of race/ethnicity for all COVID-19 cases. To develop COVID-19 response efforts that are data- and equity-driven, state and federal government agencies must mandate the collection and reporting of race/ethnicity for all COVID-19 cases.

Enforce the collection and reporting of race/ethnicity by providing resources, incentives, and penalties. State and federal government agencies must not only mandate the complete collection and reporting of race/ethnicity but also must hold stakeholders accountable with enforcement mechanisms.

Resource the overhaul of public health surveillance systems nationally. The Council for State and Territorial Epidemiologists has launched a campaign titled [*Data: Elemental to Health*](#), that calls for the federal investment in reforming and maintaining surveillance systems. The goal is to modernize public health data collection into a seamless and integrated framework, which will create a surveillance capability suitable to safeguard the health of the nation.²⁴

Standardize the collection and reporting of race/ethnicity by implementing Office of Management and Budget (OMB) 1997 standards. Implementing OMB standards for race/ethnicity is a critical first step that allows greater comparability of racial information across areas and ensures racial categories align with self-identification of race.²⁵

Avoid grouping populations in homogenizing categories such as “Other” or “Multiracial”. Grouping populations in a single racial category, such as “Other” or “Multiracial,” results in an erasure of that population in the data and, subsequently, in public health response.

Disaggregate the “Multiracial” category. It is important to disaggregate the “Multiracial” category in the collection and reporting of data to adequately capture racial identity. AI/AN are one of the largest growing multiracial groups in the U.S., and data collection and reporting should reflect this diversity.

Methods

American Indian/Alaska Native Definition

American Indian and Alaska Native (AI/AN) was defined as AI/AN alone and AI/AN in any combination of race and ethnicity.

Population Estimates

Population estimates were from U.S. Census Bureau Annual County and Resident Population Estimates, Vintage 2019,²⁶ which is likely an underestimate of AI/AN due to methods of data collection. In addition, population estimates are not representative of tribal enrollment status—U.S. Census race and ethnicity is self-reported by individuals. Only tribes can determine eligibility for tribal enrollment and decisions related to releasing tribal enrollment numbers are made on a tribe-to-tribe basis as is their right as sovereign nations.

Racial Data Definition

State COVID-19 racial data was obtained from the COVID-19 Tracking Project.²⁷ Incomplete racial data for states was defined as a case with racial status as unknown, other, or multiracial. Other and multiracial categories were deemed incomplete racial data due to the inability to disaggregate. CDC COVID-19 racial data was obtained from the CDC COVID-19 National Surveillance Data.²⁸ CDC data complies with OMB standards, which allows for the disaggregation of other and multiracial, therefore incomplete racial data for CDC was defined as a case with racial status unknown or without a race specified for other.²⁸

COVID-19 Case Definition

State COVID-19 cases were obtained from the COVID-19 Tracking Project and were defined as confirmed cases.²⁷ There were ten states* that presented COVID-19 cases as confirmed and probable without the ability to disaggregate by confirmed only, thus all were included. CDC COVID-19 cases were obtained from CDC COVID-19 National Surveillance Data and were defined as confirmed cases reported to the CDC by states.

COVID-19 case data was extracted from the COVID-19 Tracking Project and the CDC COVID-19 National Surveillance Data on January 20, 2021. State dashboards were also assessed for inclusion of AI/AN on January 20, 2021. Variations in the collection and reporting of racial data may change over time.

Some tribes have agreements in place with their respective states to withhold tribal specific data from public facing data dashboards which is their legal right as sovereign nations.

Scored Categories

An overall score was determined for each state using the following categories. These were selected because they illustrate the degree of incomplete racial data among confirmed COVID-19 cases and the discrepancy in racial data collected and reported at state and federal levels.

1. AI/AN included on the state dashboard
2. Percent of cases with complete racial information reported on state dashboard
3. Percent of confirmed cases from the state reported to CDC
4. Percent of confirmed cases with complete racial information reported on CDC database

*Alaska, Illinois, Indiana, Kansas, Montana, New Mexico, New York, Oklahoma, Oregon, and Rhode Island.

State Scores

For each category, a grade was assigned for each state. For category one, states were given a percentage of 100 if an AI/AN racial category was listed on their state COVID-19 dashboard. States without an AI/AN racial category were given a percentage of 0. For categories two and four, states were given a percentage of 0-100, which represents the percentage of confirmed cases with complete racial data. For category three, states were given a percentage of 0-100, which represents the percentage of confirmed cases reported by states to CDC. A final score was calculated by averaging the scores of all categories. The score was then assigned a letter grade with the following thresholds: A+ =97-100% ,A=93-96%, A-= 90-92%, B+=87-89%, B=83-86%, B-80-82%, C+ 77-79%, C=73-76%, C-=70-72%, D+=67-69%, D=63-66%, D-=60-62%, F= <60%.

Given the variation in the collection and reporting of racial data across states, there were a few exceptions to the scoring of categories. For example, South Carolina included AI/AN on their dashboard in a racial category labelled Asian/Alaskan/Hawaiian, which incorrectly aggregates unassociated racial groups, thus were given a score of 0% for the inclusion of AI/AN due to the inability to disaggregate by AI/AN. Kentucky included

AI/AN on their state dashboard, however, the information was not visible on the graph hindering the utility of the data. They were also given a score of 0% for the inclusion of AI/AN.

South Carolina included AI/AN on their dashboard in a racial category labelled Asian/Alaskan/Hawaiian, which incorrectly aggregates unassociated racial groups, thus were given a score of 0%

Alaska, Ohio, and Utah reported a greater number of cases to CDC then reported on their dashboard. Due to this discrepancy, we were unable to identify the percent of confirmed cases sent to the CDC, thus they were assigned a score based on the average of categories 1, 2, and 4.

U.S. Scores

For the U.S., a score for each category was generated based on the average of each state and then assigned a grade for that category. Those scores were then averaged to calculate the overall score and letter grade for the U.S.

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