

# ACHIEVING PROGRESS TOWARD HEALTH EQUITY USING RACE AND ETHNICITY DATA: State Strategies and Lessons Learned

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## INTRODUCTION

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**R**ace and ethnicity data are essential tools to identify and address health inequities. During the COVID-19 pandemic, race and ethnicity data revealed significant **inequities** across historically marginalized populations. Black, Latinx, American Indian and Pacific Islander populations experienced **higher rates** of exposure, hospitalizations and **mortality**. Similarly, data also **exposed wide disparities** in vaccination rates across racial and ethnic groups, particularly among Black and Latinx populations. Although some of these gaps have narrowed, more work is needed. States have made progress in collecting and reporting race and ethnicity data that has enabled the targeting of efforts and resources to communities. For example, the number of states reporting vaccine data by race and ethnicity increased from **17 states** in January 2021 to **47 states** in September 2021. This increase in public reporting of COVID-19 vaccine data by race and ethnicity data has informed state strategies to narrow racial and ethnic gaps in vaccination rates.

States have employed different strategies to collect and report race and ethnicity data during the pandemic. While the number of states reporting race and ethnicity data for vaccinations has increased, there remain gaps in the completeness and accuracy of these data. According to the Centers for Disease Control and Prevention's [COVID Data Tracker](#), race and ethnicity is missing for about 29 percent of fully vaccinated people across the United States. The [CDC](#) notes that missing data may result from inconsistencies in collecting race and ethnicity data at the time of vaccination, differences in electronic data programs across jurisdictions, and variations in policies or laws limiting reporting or sharing of demographic data. Similar challenges exist for [cases](#) and [mortality](#) data. Such missing data complicate the collective understanding of COVID-19's impact among historically marginalized populations and limit efforts to improve health equity. With an increasing number of states committed to improving health equity and the availability of various funding streams—including funds from the American Rescue Plan Act—states can further achieve progress toward health equity by adopting promising strategies and incorporating lessons learned during the COVID-19 pandemic.

In June 2021, the National Governors Association Center for Best Practices, the Duke-Margolis Center for Health Policy, and the National Academy for State Health Policy co-hosted a virtual summit on data and health equity. The summit convened state leaders from 20 states to discuss challenges and strategies for collecting, reporting and using race and ethnicity data to improve health equity during and beyond the COVID-19 pandemic. This issue brief summarizes state strategies and experiences shared during the convening, as well as lessons learned during the COVID-19 pandemic.

## KEY TAKEAWAYS

- ▶ State leaders adopted various strategies to improve the collection and reporting of race and ethnicity data during the COVID-19 vaccine rollout. These strategies include setting up information systems that require or facilitate the collection of race and ethnicity data, adapting policies to facilitate data sharing, combining data from existing sources and systems to fill gaps, and providing incentives to providers and health plans to collect race and ethnicity data.
- ▶ State leaders suggested future opportunities to improve the collection and reporting of race and ethnicity data, including providing clear and consistent federal and state guidance on data collection and reporting requirements, adapting race and ethnicity categories to reflect state demographics, strengthening their data infrastructure, and partnering with other entities in the collection and use of these data. In addition, states emphasized the need to increase public trust and confidence in sharing race and ethnicity data with state and local governments for public health uses.
- ▶ States can use race and ethnicity data along with other measures and tools, such as the social vulnerability index and geographic information systems, to better understand health and social inequities in the context of the physical and social landscape. States can further understand these inequities by engaging community partners and soliciting their input to contextualize the data.
- ▶ To ensure sustainability and achieve systemic change, federal, state, and local leaders can create a vision for health equity, assess and measure their progress toward health equity, and engage communities experiencing significant health inequities throughout and beyond the current pandemic.

## CHALLENGES WITH COLLECTING AND REPORTING RACE AND ETHNICITY DATA



Throughout the COVID-19 pandemic, states faced challenges with collecting and reporting race and ethnicity data, including in ensuring the reliability and completeness of these data. As noted [elsewhere](#), many of these challenges predate the current pandemic; however, the pandemic has brought additional [attention](#) to these challenges. States and experts at the convening identified the following challenges:

- ▶ **Incomplete and inconsistent collection and reporting of data.** States and localities vary widely in their standards for data collection, including for race and ethnicity categories, units of measure, and the frequency of reporting. States and localities rely on fragmented and outdated [disease-tracking systems](#), which has made it challenging to transfer data within states and with the federal government. In addition, there is a large amount of missing or unknown race and ethnicity data, [especially at the federal level](#). Furthermore, missing or incomplete data has made it difficult to conduct intersectional analyses, such as combining race and ethnicity with age or geographic location. This issue is receiving national attention with recommendations released by the [National Commission to Transform Public Health Data Systems](#), convened by the Robert Wood Johnson Foundation, as well as a set of [recommendations](#) from Grantmakers in Health and the National Committee for Quality Assurance recommending that the federal government standardize collection and reporting of race and ethnic data while allowing for flexibility at the state and local levels.
- ▶ **Public trust in sharing data with state and local governments.** Participating states highlighted that there is an urgent need to increase public confidence in reporting race and ethnicity data to state and local governments for public health purposes. Increasing public trust in sharing race and ethnicity data, particularly among historically marginalized populations, can help alleviate fears that such data may be used to generate harmful policies or programs.
- ▶ **Limitations with current standards.** Participating states highlighted limitations with the current categorization of race and ethnicity data, as set by the Office of Management and Budget. Specifically, [current standards](#) do not adequately reflect our increasingly diverse population in the United States. While the standards provide broad racial and ethnic categories, participating states noted the importance of identifying and collecting data on subgroups (e.g. nationalities) represented within states. Grantmakers in Health and the National Committee for Quality Assurance also [recommend](#) that the Office of Management and Budget review and update their standards to reflect current demographics and provide flexibility at the state and local level.
- ▶ **Challenges with data sharing.** Health care institutions can improve the accuracy and completeness of race and ethnicity data by sharing available data; however, [data sharing challenges, such as](#) legal and regulatory restrictions to accessing data, technology challenges, and limited coordination across health care institutions, can impede improvement in the accuracy and completeness of these data.

# STATE STRATEGIES TO IMPROVE THE COLLECTION, REPORTING, AND USE OF RACE AND ETHNICITY DATA DURING THE COVID-19 PANDEMIC



## Collecting and Reporting Race and Ethnicity Data for Vaccine Distribution

During the June convening, participating states shared strategies and opportunities to improve the collection and reporting of race and ethnicity data to reduce COVID-19 inequities, particularly inequities in vaccine rollout. States adopted new data systems and adapted policies to improve the collection and reporting of race and ethnicity data (see summaries of [North Carolina](#) and [Minnesota](#)). Given the gaps in race and ethnicity data and the speed at which states needed to report data on vaccine uptake, some states combined existing data sources and systems to improve data quality (see summaries of [Minnesota](#) and [Utah](#)). States underscored the importance of providing direct outreach and support to providers as well as incentives, both financial and non-financial, to encourage and improve the collection of race and ethnicity data (see summaries of [North Carolina](#), [North Dakota](#) and [Utah](#)).

Participating state leaders identified opportunities to further improve the collection and reporting of race and ethnicity data, both for ongoing vaccination efforts and beyond. Collection and reporting of race and ethnicity data could be strengthened by clear and consistent guidance at the state level on data collection standards and reporting requirements (see summaries of [North Carolina](#), [Minnesota](#) and [Utah](#)). Participating state leaders also noted the importance of federal standards that ensure consistency in the collection and reporting of race and ethnicity data across states. State leaders can also support opportunities to adapt race and ethnicity fields to reflect their state's demographics, including by adding multi-ethnic categories or including subcategories by nationalities represented in a given state (see summary of [Oregon](#)). Finally, [strengthening states' data infrastructure](#) is critical to sustaining improvements in the collection and reporting of race and ethnicity data and addressing data sharing needs (see summary of [Utah](#)). States, territories and local jurisdictions have access to funding from the [American Rescue Plan Act of 2021](#) and the [CDC](#), which is critical to strengthening their data infrastructure.



## NORTH CAROLINA

North Carolina's Department of Health and Human Services developed a chief data officer position in 2019, demonstrating the department's recognition of the importance of data. This position, the accompanying data office, and the level of leadership buy-in in North Carolina facilitated the state's response during COVID-19.

In response to COVID-19, North Carolina deployed a new Immunization Information System, called the COVID-19 vaccination management system that requires race and ethnicity data be collected for all recipients. When reporting COVID-19 vaccination data, a mandatory data entry field prevents providers from continuing with an entry without recording race and ethnicity. One possible trade off for the required data field is that paper forms must be used at vaccine events where there is no internet access. If the race and ethnicity field on the paper form is not filled out, the person entering the data must still enter something to move forward in the system—and therefore, other or unknown are typically entered. With the rollout of the new immunization system, North Carolina organized provider training sessions to ensure proper collection of vaccine data and a consistent approach to collecting race and ethnicity indicators. Senior state leadership also worked directly with hospital and health system CEOs to identify strategies to strengthen their processes. These efforts drastically increased the percentage of vaccinations with race and ethnicity data—North Carolina providers now report race and ethnicity data for 94 percent of COVID-19 vaccinations.

North Carolina state leaders clearly communicated policies mandating the collection of race and ethnicity data to all immunization providers. To further ensure data collection, the state regularly follows up with providers through an incentive-based model to boost data collection. Through this model, providers who meet a certain threshold of data collection and reporting can automate data entry. If there are missing data or inaccuracies after automation, the state provides warnings and a grace period to enter missing data or fix these inaccuracies, or they will be reverted to manual entry. So far, the state has not had to require anyone to revert to manual entry. Smaller providers with less advanced systems experienced additional challenges with inputting this data, and therefore the state offered daily and weekly office hours to share information and receive feedback. The state also sends weekly equity data reports to providers that track equitable outreach and allocation of vaccines to historically marginalized populations. This strategy promoted accountability and led to improvements in the share of vaccines given to individuals from historically marginalized populations.



## MINNESOTA

Minnesota's Immunization Data Sharing Statute (§144.3351), which describes when data can be shared without patient consent, was previously interpreted in a way that limited the state's ability to collect and share race and ethnicity data. The state reinterpreted this statute in January 2021, requiring providers to send race and ethnicity data of vaccinated individuals to the state's immunization information system when it is available.

Minnesota's largest health systems and the Veteran Affairs health system formed the Minnesota Electronic Records Consortium. With support from Minnesota's Department of Health, [the consortium](#) pools aggregate data from health systems' electronic health records to address data gaps and inform the state's public health response. While the consortium existed prior to COVID-19, the pandemic spurred the consortium into immediate action focusing on case data. They were able to pool demographic data from across each system, including information on race, ethnicity, language spoken and geography (as well as physical health and comorbidities) while ensuring the data was de-identified. For the vaccine response, the consortium also connected with Minnesota's immunization information system, reducing missing race and ethnicity data by over 30 percent for patients with at least one dose of the COVID-19 vaccine. Currently, the vaccine data is about 90 percent complete for race and ethnicity. This information is shared on a [public dashboard](#) and updated weekly.

## Using Race and Ethnicity Data to Inform COVID-19 Policy and Programs

During the June convening, participating states shared their experiences with using race and ethnicity data for equitable distribution and resource allocation. States used race and ethnicity data combined with information on COVID-19 burden, social determinants of health, and geography to inform equitable distribution and resource allocation for COVID-19 testing and vaccinations (see summaries of [North Dakota](#), [Indiana](#), [Pennsylvania](#) and [Utah](#)). In addition, states employed other measures of health equity, such as the CDC's [Social Vulnerability Index](#), to supplement missing or incomplete race and ethnicity data to drive policies and programs (see summaries of [North Dakota](#), [Indiana](#) and [Pennsylvania](#)).

States collaborated with community partners to share, interpret and act on collected race and ethnicity data (see summaries of [North Dakota](#), [Indiana](#), [Pennsylvania](#), [Oregon](#) and [Utah](#)). Many states emphasized the importance of data accessibility by providers and the public and, in response, reported race and ethnicity data on public dashboards featured on state health department websites (see summaries of [Minnesota](#) and [North Dakota](#)). The National Commission to Transform Public Health Data Systems similarly [recommends](#) that equitable governance and community engagement be prioritized in order to create a more equity-centered data system.



## NORTH DAKOTA

North Dakota set a goal of ensuring everyone in the state had access to a vaccine within 30 miles—a challenge given the frontier nature of the state. This strategy involved mapping coverage and recruiting vaccine providers in areas that had accessibility gaps. In addition, North Dakota mapped the CDC's [Social Vulnerability Index](#) and a metric measuring population intent to vaccinate to choose the location of mobile vaccine clinics and prioritize funding and resource allocation. On top of a base rate adjusted for population, counties with high social vulnerability index received additional funding and vaccine allocation. They worked closely with the state's Office of Health Equity to connect funding streams for community-based and faith-based organizations and to combine efforts on vaccinations and addressing the social determinants of health.

North Dakota encouraged providers to report demographic details and used the social vulnerability index and other measures to locate vaccination clinics and prioritize resources. North Dakota emailed race and ethnicity “report cards” to individual vaccine providers with details on their data collection completion rates. As a result, many North Dakota providers increased their rates of data collection and reporting for vaccinations. The state also publicly reports race and ethnicity rates across the state on a [dashboard](#) on their website. North Dakota uses a combination of social vulnerability index and COVID-19 vaccinations rates to evaluate the state's success and any continuing or emerging disparities. In addition, the state is monitoring vaccination rates (by tribe) for all five federally-recognized tribes in the state.

Finally, race and ethnicity data drove the development and implementation of [North Dakota's strategic plan](#) to address COVID-19 health inequities. For example, when North Dakota opened vaccine eligibility to people 65 and older, they also decided to open eligibility for American Indians 50 and older, based on data showing the pandemic's disproportionate impact on tribal communities.



## INDIANA

Indiana used the social vulnerability index [overlayed](#) with information on vaccine uptake to coordinate with local health departments and health systems so they could determine where additional vaccination opportunities were needed, especially for historically marginalized populations. In addition, Indiana provided all counties with an odds ratio for vaccination that indicated which demographic groups may benefit from enhanced direct outreach. The state also worked with counties to consider how best to strategically partner with community-based and faith-based organizations to tailor COVID vaccine messaging.

Indiana emphasized that racial and ethnic groups are not homogenous and working with diverse organizations and community leaders facilitates a broader reach. For example, after identifying that Black Hoosiers were receiving vaccines at disparate levels, they worked with the NAACP, the Urban League, pastors, coaches and others to engage the broadest array of Black Hoosiers possible. Data was used to identify target populations, but community partnerships and qualitative information were critical for identifying the strengths and needs of specific communities. In addition, Indiana also featured voices of prominent leaders in the state to ensure messaging was presented in many languages and from a variety of voices. The state invested \$1.4 million in their COVID-19 vaccine communication and media campaign.



## PENNSYLVANIA

Pennsylvania used geographic mapping early in the COVID-19 response to evaluate testing rates by race, ethnicity, age and geography. This information was used by the Department of Health and community-based organizations to improve testing and identify where sites would be best located. The commonwealth built on this work during the vaccine rollout by [overlaying](#) social vulnerability index and vaccine uptake data on state maps to identify where gaps existed, down to the zip code level. The Department of Health identified that some areas were saturated, whereas others had limited resources available. They shared this information with community partner organizations and used the data to help inform vaccination efforts. Health equity response teams, which include individuals representing state government, academic institutions, and communities, weighed in on the commonwealth's strategy for testing and vaccine roll out. In addition, Pennsylvania used behavioral risk factor surveillance data to understand social risk factors and determine the populations most susceptible to severe COVID-19 outcomes.

## STATE EFFORTS TO BUILD SUSTAINABLE STRATEGIES TO ADDRESS HEALTH EQUITY BEYOND COVID-19



**A**dvancing health equity requires systemic change, which entails addressing the root causes of health inequities as well as the systemic failures that continue to exacerbate those inequities. As states shared their experiences with using race and ethnicity data to respond to COVID-19, they also reflected on strategies to further improve health equity throughout and beyond the COVID-19 pandemic. During the convening, participating state leaders agreed that a common definition of health equity was lacking and emphasized the importance of establishing a clear definition and vision for health equity to guide their work. In addition to establishing a clear definition and vision for health equity, participating states noted the importance of acknowledging the root causes of inequities which include poverty, structural racism, and other institutionalized injustices (see summary of [Oregon](#)).

Participating states acknowledged communities as key sources for contextualizing, understanding, and using race and ethnicity data. The National Commission to Transform Public Health Data Systems also [recommends](#) “center[ing] health equity and well-being in narrative change” by identifying and engaging stakeholders to contextualize quantitative data. Examples of engaging communities, particularly those experiencing significant health inequities, include soliciting the expertise and input of community partners and funding community-based organizations most familiar with their community’s needs (see summaries of [North Dakota](#), [Indiana](#), [Pennsylvania](#), [Oregon](#), and [Utah](#)). By engaging communities experiencing significant disease burden and health inequities, states can determine the most effective ways to collect race and ethnicity data, can better contextualize race and ethnicity data to understand health inequities, and can design and tailor interventions using community input.



## OREGON

The Oregon Health Authority established a [strategic goal](#) “to eliminate health inequities in Oregon by 2030.” Every decision the agency makes is considered within the context of whether it will help accomplish that goal. With a focus on social justice, the Health Authority plans to accomplish this goal by focusing on distributing and redistributing resources and power through conscious, antiracist efforts and actions. State officials acknowledged the agency is still learning, as fully understanding the challenges is a big undertaking, but they are working to create an actionable plan.

The Health Authority has made it a priority that people have a right to see themselves in the data and in the questions being asked of them, and focuses on government as a steward of data rather than as the owner of data. As a steward of data, the authority collaborates with community-based organizations to contextualize the data being collected. Oregon has been working to disaggregate race, ethnicity, language and disability data collections to a greater extent, in response to concerns raised by community groups. In 2017 Oregon developed the [Race, Ethnicity, Language, and Disability \(REALD\) demographic data collection standards](#) which includes collecting and reporting 39 options for race and ethnicity to better reflect the identities of individuals in their communities. The Oregon state legislature passed HB 4212 in 2020 requiring providers to submit this demographic data with COVID-19 test results. Oregon also added questions on sexual orientation and gender identity to their data collection as part of contact tracing efforts. Based on their experience with collecting demographic data from providers, Governor Kate Brown in Oregon recently signed [HB 3159](#) into law that would expand the data standards to include sexual orientation and gender identity, building upon the questions used for COVID-19 data reporting. HB 3159 also directs the Oregon Health Authority to create a centralized registry to receive data annually from providers and insurers for all patients. The authority will also be receiving funds from the legislature this year to further support its data collection efforts and strengthen its data infrastructure. They will be able to fund about 44 additional positions, about 20 of which will support the implementation of [HB 3159](#).

Oregon recently incorporated a [health equity metric](#) as part of the Coordinated Care Organization incentive measures. The metric emphasizes “meaningful language access to culturally responsible health care services” and monitors access to quality spoken and sign language interpreter services for beneficiaries covered by the Oregon Health Plan (Oregon’s Medicaid program). Although early in its implementation phase, Oregon’s metric has been helpful in identifying Medicaid beneficiaries in need of interpretive services. As a measure designed to assess programmatic impact, Oregon’s health equity metric not only aims to identify inequities in access to care, but also provides a pathway to address those inequities through incentives tied to the metric. Oregon is also reviewing the rest of the Coordinated Care Organization incentive measures to identify which ones are building toward health equity and plans to integrate the voice of Medicaid members into the metric selection and retirement process. Furthermore, Oregon is working toward developing Oregon specific incentive metrics that focus on upstream factors affecting health, including social determinants of health, to further improve health equity.



## UTAH

In response to COVID-19, Utah increased reported race and ethnicity immunization data from 70 percent to 88 percent by linking data from the state immunization system to EpiTrax, its disease surveillance program. Utah developed tools to collect race and ethnicity data that were informed by their multicultural committee which were then shared with providers. [Utah’s Vaccine Equity Roadmap](#) helps guide immunization providers on effective reporting and use of race and ethnicity data during vaccine distribution. The roadmap used the state’s [Health Improvement Index](#), a composite measure of social determinants of health, geographic area, and the percentage of racial-ethnic minorities within that area, along with community feedback to create their priorities and guidance for providers. The roadmap is a living document and is updated as the state and their community partners continue learning new data.

Utah acknowledges that health equity data is not just about quantitative information and that understanding the context of the data is also important, as is how the information is collected, analyzed, and reported. Utah’s health officials worked with community health workers in the state to create a community health worker collaborative. In addition, they funded community-based organizations and local health departments statewide to work with or directly hire community health workers. Utah’s health officials met weekly with the community health worker collaborative, providing COVID-19 related training, and receiving feedback from the community health workers to provide context to the quantitative data they were collecting through their public health surveillance efforts.

In addition, Utah’s health officials are considering how to sustain this work beyond the current pandemic, including by further enhancing their data infrastructure. Using funding from the CDC, the state aims to strengthen its public health data infrastructure by building a robust internal infrastructure at the state and local levels that mobilizes data, research, and evaluation and by facilitating data exchange across agencies. In addition, Utah’s health officials plan to facilitate data exchange by promoting collaboration across agencies and health care systems. To do so, Utah’s health officials will identify the needs and priorities for demographic data and social needs across health care systems.

# ASSESS NEEDS AND MEASURE PROGRESS TOWARD HEALTH EQUITY



Participating states identified the importance of assessing their populations' needs and measuring progress toward achieving health equity goals. RWJF's National Commission to Transform Public Health Data Systems also [recommends](#) that public health measurements capture and address inequities. All states represented at the convening used surveillance data disaggregated by race and ethnicity to track and address health inequities. In addition, some states have started to use health equity metrics (see summaries of [Oregon](#) and [California](#)) and place-based vulnerability indices (see summaries of [North Dakota](#), [Indiana](#) and [Pennsylvania](#)) to assess and monitor their state's progress toward health equity. To avoid limitations of certain health equity metrics and place-based vulnerability indices such as the CDC's original SVI, states can use updated metrics such as the [Minority Health Social Vulnerability Index](#), which combines 15 social factors included in the original CDC social vulnerability index along with factors known to be associated with COVID-19 outcomes and specific race and ethnicity categories and languages. However, more work is needed to develop models and examples of how states can establish a "baseline" and evaluate progress toward health equity goals.



## CALIFORNIA

During the COVID-19 pandemic, the **California** Department of Public Health developed a [health equity metric](#) that measured the COVID-19 positivity rate in the most disproportionately affected communities. According to [California's Blueprint for a Safer Economy](#), counties were only able to reduce COVID-19 mitigation requirements if test positivity rates in a county's most socially and economically vulnerable census tracts did not lag behind the county's overall test positivity rate. Race and ethnicity data [were not included](#) within the composition of the metric, thus creating some limitations and delays in understanding and addressing inequities within the state. The metric did focus on identifying areas with low median income, low education levels, and limited health care access, which are often correlated with poor health outcomes. This metric played an important role in California's reopening strategy and set a precedent for future efforts to measure health equity.

## CONCLUSION

Although the COVID-19 pandemic continues, with the spread of COVID-19 variants, particularly among unvaccinated individuals, states are looking toward recovery with COVID-19 as a constant not a crisis. While COVID-19 inequities have narrowed, broader health inequities across states continue to persist. By improving the availability of and reducing the inconsistencies with race and ethnicity data, states can better understand inequities exacerbated by COVID-19 and develop effective public health interventions. Participating states in our June summit shared strategies that can further boost the collection, reporting and use of race and ethnicity data across states. Participating states also showed that states can achieve progress toward health equity by committing to a vision to eliminate health inequities, by assessing and measuring their progress toward health equity, and engaging communities that are disproportionately affected by COVID-19 inequities. These lessons learned are critical as states chart their path forward toward recovery and can inform strategies to eliminate health inequities in the long term, beyond the pandemic.



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