

# Follow the Data

## HOW RACE & ETHNICITY DATA TRAVEL THROUGH THE SYSTEM (AND GET LOST ALONG THE WAY)

Race is a social construct and racial health disparities stem from structural racism, not from inherent biological differences. Comprehensive health, socioeconomic, and other contextual data disaggregated by race and ethnicity are critical to addressing disparities. This graphic focuses on race and ethnicity data and the numerous barriers in today's healthcare system that result in missed opportunities to understand the full scope of health disparities in racially and ethnically diverse communities. In addition to barriers at a specific stage of data flow, lack of interoperability may interfere with sharing data amongst organizations and create potential for data loss. Additionally, incomplete and/or inaccurate data may be passed along at any step in the process. Although state and/or federal mandates can facilitate improved data, better enforcement and consistency across states is needed for impact. This graphic shows barriers and missed opportunities in one disease state: COVID-19.

A self-identifying Cuban female insured through a Medicaid managed care plan presents to a primary care clinic with suspected COVID-19.

**Provider**  
Race & ethnicity data recorded as Race: White, Ethnicity: Hispanic or Latino via recorder observation on patient intake form using 1997 OMB standardized question set

**Barriers to Data Quality:**

- Self-identification is not used
- Separate race & ethnicity questions (1997 OMB standard) go against emerging best practices
- Lack of granularity in response options (e.g., may not be able to indicate "Cuban")

**Barriers to Data Collection:**

- Lack of staff capacity or resources to train staff
- Patient may mistrust provider
- Provider may fear collecting race & ethnicity data and/or believe it is not important to their own practice

**Barriers to Both:**

- Language or literacy barriers may or may not be present; this contextual data may not be recorded

impact. This graphic shows barriers and missed opportunities in one disease state: COVID-19.

**COVID-19 testing Lab (commercial/external)**

**Barriers to Reporting:**

- Race & ethnicity data may not be sent with sample

**Barrier to Data Quality:**

- EHR might have a pre-populated default option for race & ethnicity

**Barriers to Data Collection:**

- EHR may lack a data field for race & ethnicity
- Race & ethnicity may require manual input into EHR

**Electronic Health Record (EHR)**

EHR data (e.g., lab results, race & ethnicity) might be made available to some researchers (and perhaps with a fee).

Availability and completeness of race & ethnicity data in EHRs varies widely. One study found race/ethnicity data availability ranged from 28.1% to 99.2% in sample EHRs.

**Medicaid Managed Care Organization**

**Barriers to Data Collection:**

- Race & ethnicity data irregularly accompanies claims submission

**Barriers to Data Collection:**

- 23 states have APCD's in operation or active implementation
- An additional 6 states have APCD's with voluntary data collection efforts.

**Barriers to Reporting:**

- Differences in laws and policies across states and local areas, each dictating to which agencies labs send their data, leads to increased reporting complexity; some labs must additionally report to CDC
- Race & ethnicity may not accompany all test results; however, public health departments are expected to use HIEs to fill in missing data
- May not be able to send data electronically; data may be lost during manual entry process

**Barriers to Data Collection:**

- Lack of incentive for payers to collect or report race & ethnicity data
- May be difficult to aggregate different race & ethnicity categories across data collectors

**State Medicaid Agency**

**Barriers to Reporting:**

- States may be able to resolve data gaps by linking to eligibility files, but data is often missing

**State All Payer Claims Database (APCD)**

Data is not made public for all states. When available, researchers must submit a data request.

**Local Health Department (or tribal/territorial)**

Some cities and local health departments make data available on their website or a public dashboard that shows cases by race/ethnicity.

**Barriers to Reporting and Analysis:**

- Time lag in data sharing between local and state agencies
- Might have to aggregate granular race and ethnicity data to protect identities in small populations

**State Health Department**

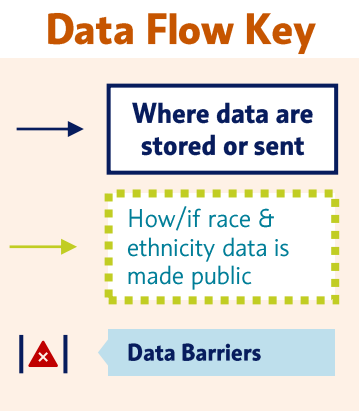
Most states display data (including race & ethnicity) via a website or public dashboard; however, race & ethnicity data may be incomplete or unknown for the reasons shown on this graphic. These data sets are sometimes available for download.

**Barriers to Analysis:**

- Categories may not be comparable across states
- Data is aggregated and loses granularity

**CDC HHS**

CDC makes data available on a public dashboard, although a significant amount of the race & ethnicity information is missing. 51 out of 56 jurisdictions report race and ethnicity data; however, some of them report this data for less than half of cases. Although HHS established requirements to improve race & ethnicity data for COVID-19 test results, research suggests it is not having a major impact.



**Barriers to Data Access:**

- Data is not made readily available to the public and requires a request to be made
- Request for data access often requires a fee
- Data request timeline can take several weeks, and in some cases several months.

Data is not made public. Researchers must complete a data use agreement to request T-MSIS Analytic Files and Medicaid Analytic Extract files.

In 2018, CMS reported at least "medium concern" for all states regarding the percent of missing race & ethnicity data. Four states were classified as having "unusable" data.



# A VISION FOR

# Better Data Flow

HOW GOVERNMENT ENTITIES, HEALTH SYSTEMS, AND PAYERS CAN IMPROVE THE FLOW OF RACE & ETHNICITY DATA (AND ULTIMATELY REDUCE DISPARITIES)



Collecting and reporting comparable, granular data is a crucial step in reducing racial health disparities that have stemmed from structural inequities. All stakeholders must implement best practices and standards to facilitate improved data quality in order to address these disparities. Ultimately, solving race and ethnicity data gaps will require collective action from all stakeholders. Each stakeholder should reflect on what part they play and take action to create a better flow of data.

## Government Entities



- 1. Enforce minimum standards:** Revise, promote, and enforce minimum standards for collecting race and ethnicity data and certify interoperable systems based on emerging best practices.
- 2. Mandate data sharing:** Implement policies that mandate race and ethnicity data sharing within and between stakeholder groups and that incentivize the use of interoperable systems.
- 3. Increase funding:** Increase funding for the thorough investigation of race and ethnicity data gaps so that, for example, researchers can attain meaningful sample sizes for small, isolated populations.

## Health Systems



### System Level

- 1. Standardize methods:** Standardize data collection methods to align with best practices and government requirements.
- 2. Implement trainings:** Implement cultural competency and skills trainings to support data collection and usage efforts.
- 3. Invest in interoperable systems:** Use and advocate for interoperable systems that support the collection, use, and reporting of race and ethnicity data.

### Individual Level

- 1. Promote disaggregation:** Help leadership understand the value of disaggregating data by race and ethnicity.
- 2. Build trust:** Build trust with racially and ethnically diverse populations, such as recruiting diverse staff for leadership roles.
- 3. Be introspective:** Be introspective to understand how one's own experiences and implicit biases may play a role.

## Payers



- 1. Standardize methods:** Standardize data collection methods to align with best practices and government requirements.
- 2. Increase collaboration:** Improve interoperability and collaboration, such as developing payer-provider partnerships to address race and ethnicity data collection and use.
- 3. Incentivize better collection:** Incorporate incentives that promote better data collection, such as implementing performance metrics around race and ethnicity data collection or collecting these data upon member enrollment.