



Addressing Gaps in Public Health Reporting of Race and Ethnicity Data for COVID-19:

Findings & Recommendations Among 45 State & Local Health Departments



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The assessment was conducted under a Public Health Emergency (PHE) Paperwork Reduction Act Waiver for COVID-19 (exclusion: 21st Century Cures Act Sec. 3087) as the data collected through this assessment will provide an understanding of the gaps and barriers in public health reporting of race and ethnicity data specific to the COVID-19 response.¹

A Note on Health Inequities in Data: Differences in health outcomes among racial and ethnic groups are due to long-term structural racism, not biological or personal traits.

Structural racism – including the longstanding racist policies and discriminatory practices across institutions, including government agencies, and society – impedes the ability of various racial and ethnic groups to equally access the vital resources (such as health care, housing, and food) and opportunities (such as employment and education) that promote overall health and well-being. The disproportionate impact of COVID-19 highlights how these inequities negatively influence health outcomes.

¹This statement was adapted from the New York City Department of Health and Mental Hygiene: <https://www1.nyc.gov/site/doh/data/data-home.page>

EXECUTIVE SUMMARY

Background

Public health data reveal that the COVID-19 pandemic disproportionately affects people from racial and ethnic minority groups. Public health’s ability to identify and address such health inequities relies on the collection and reporting of complete and accurate race and ethnicity data for COVID-19; however, gaps in the public health reporting of these critical data have been observed at both the local and national level. Reporting to public health agencies occurs through a variety of reporting pathways, including case surveillance, laboratory reporting, syndromic surveillance, and immunization surveillance. It is necessary to explore the systemic factors contributing to the gaps in race and ethnicity data for COVID-19 – including where in the reporting stream these factors arise – in order to implement targeted, effectual, and well-resourced solutions that ultimately promote health equity for all.

The Council of State and Territorial Epidemiologists (CSTE) conducted an assessment to identify the factors that are impacting the completeness and quality of race and ethnicity data for COVID-19 at public health agencies, as well as the solutions that may help mitigate these limiting factors. The assessment was completed by State Epidemiologists and designated staff at state, territorial, local, and tribal public health agencies and focused on three key objectives:

KEY OBJECTIVES

- 1 IDENTIFYING** the high-level factors impacting state, territorial, local, and tribal public health agencies’ ability to obtain meaningful race and ethnicity data for COVID-19 from healthcare providers, laboratories, and other mandated reporters.
- 2 UNDERSTANDING** which factors affect jurisdictions’ ability to send all obtained race and ethnicity data for COVID-19 on to the Centers for Disease Control and Prevention (CDC).
- 3 DOCUMENTING** successes and potential solutions for improved reporting of race and ethnicity data for COVID-19 across the public health spectrum.



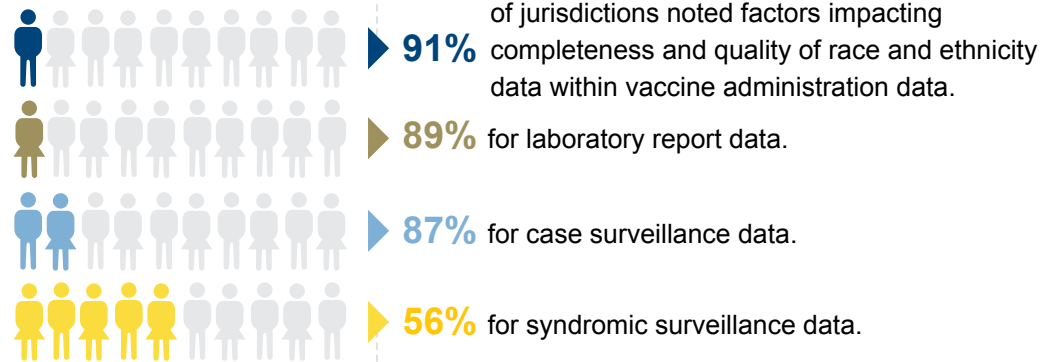
These objectives were assessed across FOUR surveillance domains:

- Case surveillance data
- Laboratory report data
- Vaccine administration data
- Syndromic surveillance data

Report Highlights

CSTE received assessment responses from 45 unique jurisdictions. The overwhelming majority of respondents indicated that they were experiencing factors that limited their public health agency's ability to obtain complete and accurate race and ethnicity data for COVID-19:

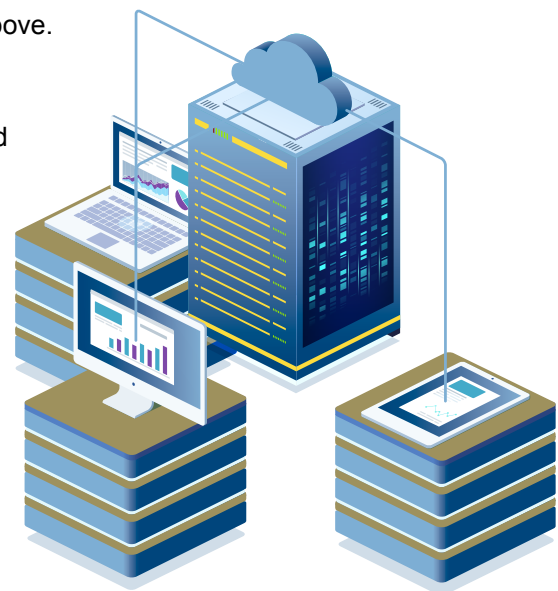
When public health agencies experience factors that limit the flow of race and ethnicity data, they have a less complete picture of the populations they serve.



At the time of the assessment, many jurisdictions had already implemented a State or local law, rule, or regulation that explicitly requires reporting race and ethnicity data for COVID-19 to the public health agency. While both State and federal mandates can be useful tools to facilitate reporting, it is evident that requirements alone are insufficient and additional factors must be addressed. Respondents identified the following factors that significantly impair their ability to obtain epidemiologically meaningful race and ethnicity data:

- Patient hesitation to indicate their race or ethnicity at the point of data collection.
- Reporters not providing data to public health agencies for various reasons.
- Information system limitations at the both the point of data collection and the public health agency.
- Limited resources or staffing at the public health agency, which exacerbates the ability to effectively address all of the above.

Respondents also surfaced a crosscutting need for uniform standards and interoperability across data systems. Factors and solutions identified by respondents have cascading effects on data quality and utility, and frequently occur upstream of the state or local public health agency – typically at the point of data collection. The full assessment report explores these factors in greater detail and documents both experientially and hypothetically helpful solutions. Finally, although the assessment focused specifically on race and ethnicity data for COVID-19, the disproportionate impact of disease on various racial and ethnic groups is not singular to COVID-19. It is imperative to understand and improve incomplete and inaccurate reporting of race and ethnicity data across all conditions.



Summary of Recommendations

In response to the assessment findings, CSTE developed the following recommendations for improving gaps in public health reporting of these critical demographic data.

Mitigate patient hesitance to indicate race and ethnicity for COVID-19 at the point of data collection:

- Evaluate current race & ethnicity data collection specifications across jurisdictions and identify opportunities to expand response options and value sets.
- Convene representatives from public health, providers, health equity advocacy groups, interpreters, and other relevant stakeholders to discuss historical context and patient concerns regarding collection of race and ethnicity data. Develop trainings and guidance for healthcare providers, test site personnel, vaccine administrators, contact tracers, and other staff on how to request race and ethnicity data from patients in a culturally appropriate way.
- Develop educational materials including trainings, webinars, and handouts with input from relevant communities that highlight the importance of collection and reporting race and ethnicity data to public health.

Encourage providers to collect and report race and ethnicity data for COVID-19:

- Define race and ethnicity as required fields in data collection forms and systems and allow collection and storage of multiple values.
- Create standardized specifications for collection and mapping of race and ethnicity data. Encourage jurisdictions to implement a universal set of standardized specifications for the collection of race and ethnicity data from reporters.
- Require providers and other test order submitters to complete race and ethnicity upon order of COVID-19 lab test.
- Assess laboratories to better understand current capability and barriers of information systems to capture, store, and transmit race & ethnicity data. Provide technical assistance and funding to ensure laboratory information systems have the capability to capture, store, and transmit multiple values for race and ethnicity data. Incentivize laboratories to implement current Health Level Seven International (HL7) messaging standards to transmit laboratory report data electronically to the public health agency.
- Provide technical assistance and dedicated funding to public health agencies to establish and maintain electronic case reporting (eCR) feeds. Promote and incentivize adoption of eCR by healthcare providers.
- Tie provider incentives to reporting of complete race and ethnicity data in a manner consistent with standardized specifications.

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Summary of Recommendations

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Improve information system capability to collect, store, manage, and transmit race and ethnicity data for COVID-19:

- Enable public health surveillance systems to capture and store multiple race and ethnicity values. Enable all public health surveillance systems to accept HL7 messages.
- Explore technologies to centralize mapping and translation of local codes for race and ethnicity into the standardized codes specified by public health agencies.
- Conduct an environmental scan of databases to assess completeness and utility of included race and ethnicity data. Provide best practices and functional requirements for public health agencies to access databases and perform automated matching.
- Consider the use of imputation as an adjunct method to improve completeness of race and ethnicity data.
- Provide resources to for public health agencies to develop automated qualitative assurance tools and dashboards.

Bolster resources and staffing at the public health agency:

- Evaluate and provide guidance to public health agencies on best practices for summarizing, compiling, and analyzing race and ethnicity data.
- Allow flexibility and contracting assistance to hire additional staffing to support data collection, validation, mapping, and management.
- Build in sustained and flexible funding for information systems improvements and for hiring, training, and retaining an informatics-competent workforce to maintain information systems.



INTRODUCTION

Gaps in Public Health Reporting of Race and Ethnicity Data for COVID-19

The COVID-19 pandemic is categorically the shared experience of our lifetime. However, despite the seeming universality of this new threat, current data convey that we do not all share equally in the burden of disease. People from racial and ethnic minority groups² are disproportionately affected by COVID-19 for nearly every health outcome, including higher rates of morbidity, greater severity of symptoms and increased rate of hospitalization, decreased access to mitigation measures, and increased mortality^{3,4}. In response to these troubling data and recognizing public health's imperative to promote health equity for all, the Centers for Disease Control and Prevention (CDC) developed the COVID-19 Response Health Equity Strategy as a roadmap to reduce the burden of COVID-19 among populations at increased risk for poor health outcomes and to develop a coordinated approach to address health inequities.⁵

One fundamental component of the CDC strategy is to expand the evidence base, including the completeness and accuracy of race and ethnicity data reported to state, territorial, local, and tribal (STLT) public health agencies for COVID-19. As public health authorities, STLT public health agencies routinely receive surveillance data from healthcare providers, laboratories, and other entities for COVID-19. Reporting to public health agencies occurs through a variety of reporting pathways:

- **CASE SURVEILLANCE:** Healthcare providers, laboratories, hospitals, and other entities routinely provide case data to STLT public health agencies for reportable conditions. Reporting requirements are specified within each state or territory's reporting laws, and requirements may vary across jurisdictions. Case reports to STLT public health agencies are often triggered by clinical criteria, diagnoses, and/or laboratory test results. Data for case surveillance are typically sourced from electronic health record (EHR) systems but are often reported via paper, fax, phone calls, web portals, and sometimes via electronic case reporting. Cases of reportable disease are often significantly underreported.
- **LABORATORY REPORTING:** In addition to hospital or healthcare facility-based laboratories, diagnostic and screening tests may be conducted by academic laboratories, commercial laboratories, state and local public health laboratories, and less traditional testing partners. Patient information and corresponding laboratory test data are stored within laboratory information management systems (LIMS). LIMS may or may not interface with EHR systems. For reportable conditions, laboratory data are reported to STLT public health agencies through a variety of mechanisms, including fully or semi-automated electronic laboratory reporting (ELR), web portals, spreadsheets, and faxed paper reports.
- **SYNDROMIC SURVEILLANCE:** In order to monitor health trends in real-time, STLT public health agencies receive de-identified data from emergency departments, urgent care centers, pharmacies, and other administrative data sources. Syndromic surveillance data are generated when individuals seek medical treatment, and often include patient demographics, chief complaint and diagnosis data, and geographical location.

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² The term "people from racial and ethnic minority groups" includes people of color with a wide variety of upbringings, accomplishments, backgrounds, and experiences, who are commonly impacted by social determinants of health in a negative and inequitable way.

³ "Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity." Updated Sept 9, 2021. <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html#footnote01> (accessed Sept. 10, 2021).

⁴ "Demographic Characteristics of People Receiving COVID-19 Vaccinations in the United States." <https://covid.cdc.gov/covid-data-tracker/#vaccination-demographic> (accessed Sept. 10, 2021).

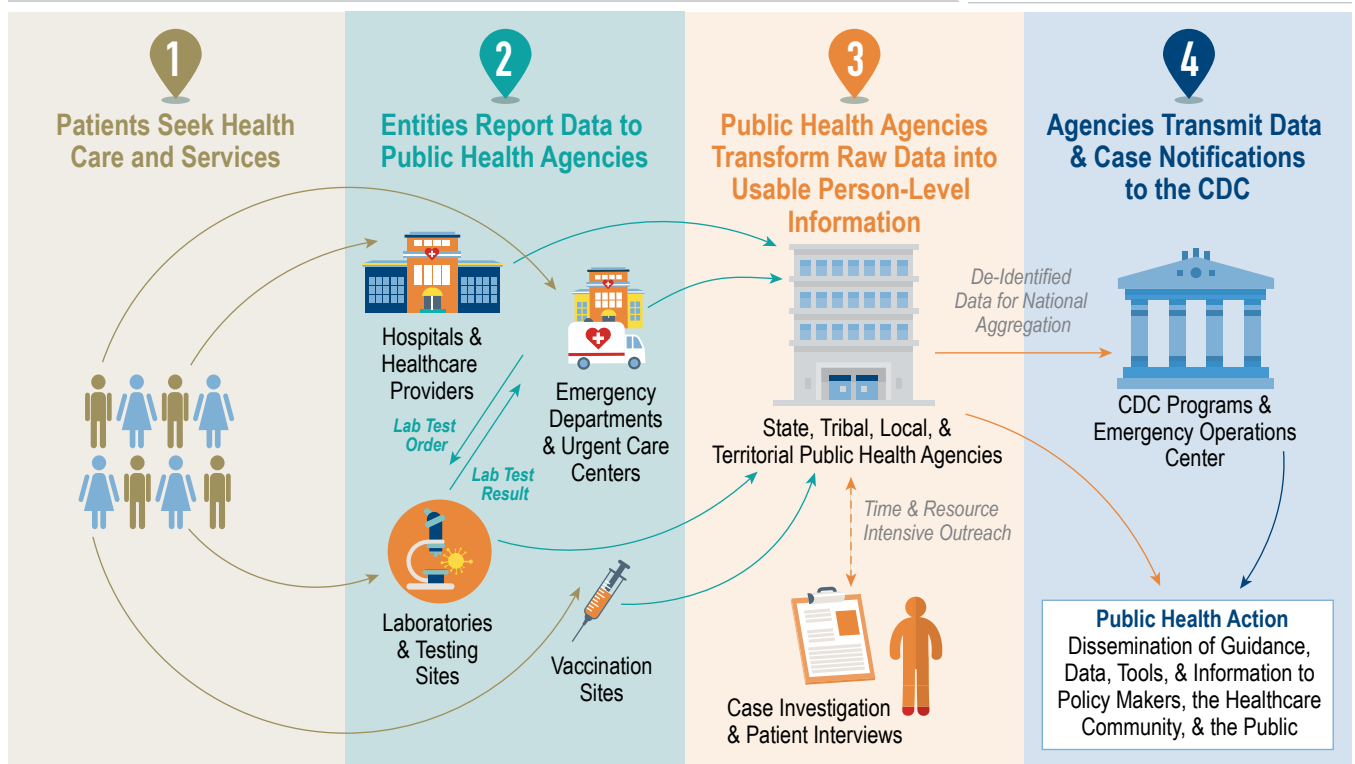
⁵ CDC COVID-19 Response Health Equity Strategy: Accelerating Progress Towards Reducing COVID-19 Disparities and Achieving Health Equity." July 2021. <https://www.cdc.gov/coronavirus/2019-ncov/downloads/community/CDC-Strategy.pdf> (accessed Sept. 18, 2021).

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- **VACCINE ADMINISTRATION:** Many jurisdictions require reporting of vaccinations to immunization registries. Reports are received from providers conducting vaccinations, including medical providers, hospitals, pharmacies, and mass vaccination sites. Vaccination data in immunization registries are often highly complete for children, but with the exception of SARS-CoV-2, vaccination data for adults are not always complete.

Following processing and enumeration at the public health agency, jurisdictions voluntarily transmit de-identified data for COVID-19 to the CDC. The CDC uses the data to identify trends in disease transmission, morbidity, and mortality; develop national guidance and targeted programs; inform policies and decision-making to guide public health response; and share data with the public via surveillance reports, online data visualization tools and dashboards, and the provision of public-use data sets.

How Does Data Flow for Public Health Reporting?



Public Health Reporting By the Numbers

- 1 Patients Seek Health Care and Services:** Healthcare entities collect person-level information (including demographic data) in their interactions with the patient, and the data are stored within respective information systems. Certain information systems may contain several types of data (e.g., clinical data, lab data, vaccination data) depending on services provided. Some services, such as lab testing, may be referred out.
- 2 Entities Report Data to Public Health Agencies:** For suspect cases of reportable conditions, relevant data are reported to public health via various reporting mechanisms.
- 3 Public Health Agencies Transform Raw Data into Usable Person-Level Information:** Public health agencies receive and consume the raw data into their information systems. Data are processed, validated, and transformed to enable analysis, public health action at the local level, and subsequent transmission to the CDC. Missing data must be obtained.
- 4 Agencies Transmit Data & Case Notifications to the CDC:** For nationally notifiable conditions, public health agencies voluntarily transmit data to the CDC for national aggregation, analysis, and decision making.

The missingness of race and ethnicity data for COVID-19 was recognized relatively early in the pandemic, accentuated by substantial increases in the volume of case and laboratory reporting across many data systems. Efforts have since been made to improve completeness of race and ethnicity data. However, some gaps still remain, the extent of which vary based on the data source. Based on estimates of national COVID-19 data as of August 2021:

- Race and ethnicity data are the most complete in **syndromic surveillance** based on emergency department visits (91% complete for race, 81% complete for ethnicity, and 77% complete for both race and ethnicity together)⁶.
- Completeness of race and ethnicity data is less complete in **case surveillance data** (74% complete for race, 65% complete for ethnicity, and 64% complete for both race and ethnicity together).⁷ At the national level, case notifications are sourced from jurisdictions and combine data from multiple sources, including case reports, case investigations, and ELR.
- Race and ethnicity data from COVID-19 **vaccine administration** programs is 62% complete⁸.
- Race and ethnicity data are often incomplete in **electronic laboratory reports (ELR)** (29% complete)⁹. This presents a challenge for conditions such as COVID-19 where ELR is the sole source of reports for the majority of cases.

These gaps in completeness at the national level indicate that there are likely challenges at the state and local level affecting public health agencies' ability to obtain, analyze, and report complete race and ethnicity data from healthcare providers, laboratories, and other mandated reporters. To better understand these challenges, the Council of State and Territorial Epidemiologists (CSTE) conducted an assessment to identify the factors that are impacting the completeness and quality of race and ethnicity data for COVID-19 at STLT public health agencies and subsequently transmission of those data to CDC. This report will outline major findings of the assessment, identify potential solutions for mitigating these factors, and provide high-level recommendations to bridge gaps in public health reporting of these crucial data.

Complete, accurate, and representative race and ethnicity data are imperative to public health efforts to combat health inequities. While the COVID-19 pandemic has harshly illuminated these differential outcomes, the disproportionate impact of disease on certain communities is not singular to COVID-19. Efforts to understand and improve incomplete and inaccurate reporting of these data advance all disease surveillance efforts.

⁶ National Syndromic Surveillance Program (NSSP) data. (August 2021)

⁷ CDC COVID-19 line-level case data. (August 2021)

⁸ CDC COVID-19 jurisdictional Immunization Information Systems. (August 2021)

⁹ CDC COVID-19 Electronic Laboratory Reporting (CELR) data. (August 2021)

ASSESSMENT SCOPE AND METHODS

The assessment content was developed in March 2021 via a series of CSTE-convened workgroup calls comprised of subject matter experts in public health surveillance and informatics, with engagement from multiple key stakeholder groups, including: the CSTE COVID-19 Data Preparedness Workgroup, the CSTE Health Equity Subcommittee, the CSTE Tribal Epidemiology Subcommittee, the National Syndromic Surveillance Program (NSSP) Community of Practice Race and Ethnicity Data Quality Workgroup, and the CDC COVID-19 Emergency Response.

Acknowledging the complexity of race and ethnicity data and the numerous touchpoints across the entire health ecosystem, the scope and objectives of the assessment were intentionally limited to:

1. Identifying the high-level factors impacting STLT public health agencies' ability to obtain meaningful race and ethnicity data for COVID-19 from healthcare providers, laboratories, and other mandated reporters. The following factors were assessed and are not mutually exclusive:

- Legal barriers that explicitly prohibit, limit, or suppress collection of race and ethnicity data.
- Information system limitations.
- Insufficient guidance, requirements, and standards for data collection and coding.
- Reporters not providing data for various reasons.
- Patient hesitation to indicate their race or ethnicity.
- Limited resources at the public health agency.
- Other factors as specified by respondents.

2. Understanding which factors affect jurisdictions' ability to send all obtained race and ethnicity data onward to the CDC. The following factors were assessed and are not mutually exclusive:

- State law that limits or prohibits further sharing of race and ethnicity data.
- Agency policy that limits or prohibits further sharing of race and ethnicity data.
- Race and ethnicity data can only be sent to CDC in aggregate.
- Information system issues.
- Additional data processing needs.
- Limited resources or staffing at the state public health agency.
- Other factors as specified by respondents.

3. Documenting successes and potential solutions for improved reporting of race and ethnicity data for COVID-19 across the public health reporting spectrum. The following solutions were assessed:

- Financial incentives for reporters.
- More guidance and education on the benefits of reporting more complete race & ethnicity data.
- Information system improvements.
- More inclusivity in race and ethnicity values sets and ability to store multiple values.
- Changes to State requirements.
- Requirements by the Department of Health & Human Services (HHS) not already identified, including by the Centers for Medicaid & Medicare Services (CMS) Clinical Laboratory Improvement Amendments (CLIA).
- Other solutions as identified by respondents.

The assessment comprised a mixture of quantitative questions to enumerate the scope of identified factors and open-ended questions to further contextualize responses¹⁰. Objectives were evaluated across four surveillance domains: 1) case surveillance data, 2) laboratory report data, 3) vaccine administration data, and 4) syndromic surveillance data. The resulting assessment instrument was developed into an online format using Qualtrics® software and distributed electronically in May 2021. The assessment was distributed to the State Epidemiologist and relevant staff (e.g., Surveillance/Informatics point of contact, ELR coordinator, COVID-19 immunizations coordinator, etc.) in all 50 state health departments, the District of Columbia, US territories, and the Federated States of Micronesia. The assessment was also distributed to several large local health departments for response. Data collection remained open for three weeks and respondents were asked to submit one complete assessment response per jurisdiction. Quantitative data and qualitative data were cleaned and analyzed in Microsoft Excel.

¹⁰ The full assessment instrument can be referenced in the appendix.

ASSESSMENT FINDINGS

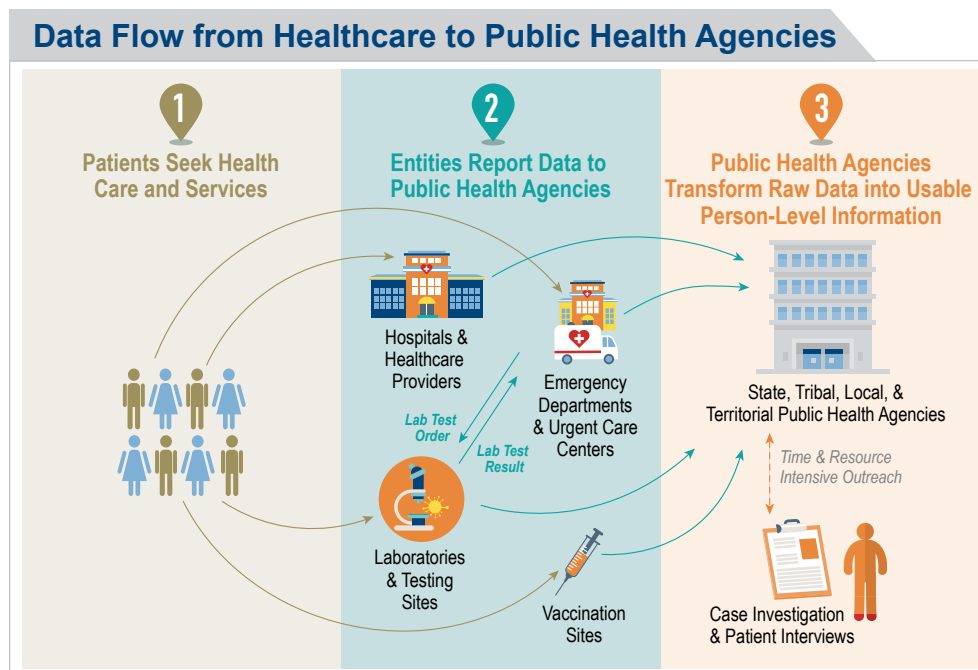
At a Glance

What Factors Impact the Completeness and Quality of Race and Ethnicity Data for COVID-19 at the State, Territorial, and Local Public Health Agency?

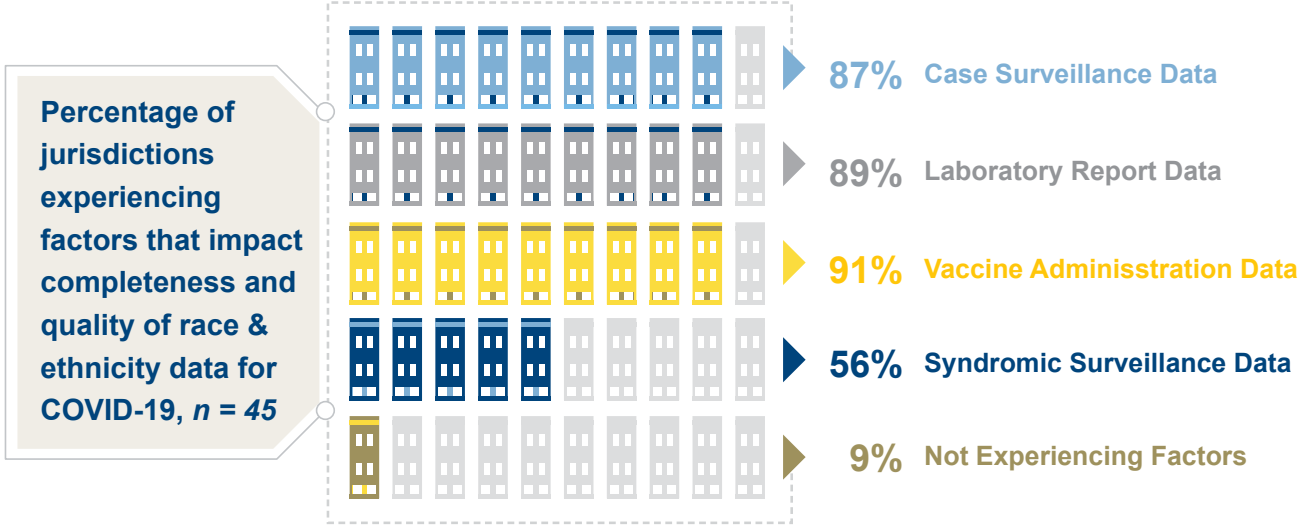
CSTE received assessment responses from 45 unique jurisdictions, including 36 States, Washington DC, Guam, and 7 large local health departments. The response rate was 72% for States, 13% for territories, and 30% for large local public health agencies, including the District of Columbia.

Race and ethnicity data for COVID-19 are essential for several public health functions at the state and local level. Respondents indicated that their agencies utilize race and ethnicity data in the following ways:

- Identifying disparities in disease incidence and burden (e.g., severity, hospitalization, and mortality) across racial and ethnic groups.
- Preparing stratified reports for governmental leadership and partners.
- Understanding access to preventive measures such as vaccination or treatment across racial and ethnic groups.
- Applying an equity lens to all activities within the public health agency.
- Tailoring culturally appropriate messages for feedback and prevention for specific populations.
- Targeting response activities to communities and people of races or ethnicities with the highest disease burden and to resolve inequities driven by structural racism and systemic injustices.



Obstacles that prevent public health agencies from collecting complete race and ethnicity data greatly harm our ability to illuminate and address health inequities. Therefore, it is striking that the overwhelming majority of respondents indicated that they were experiencing factors that limited their public health agency’s ability to obtain complete and accurate race and ethnicity data for COVID-19. By surveillance domain, 91% of jurisdictions noted factors impacting completeness and quality of race and ethnicity data within vaccine administration data, 89% for laboratory report data, and 87% for case surveillance data, and 56% for syndromic surveillance data. Only 9% of jurisdictions indicated that they were not experiencing any factors that limited their agency’s ability to obtain complete race and ethnicity data.



Several factors at varying junctions of the public health reporting stream were identified as contributors to the observed paucity of meaningful race and ethnicity data for COVID-19. **Table 1** describes the percentage of respondents who indicated that a particular factor was affecting their state or local public health agency’s ability to obtain complete race and ethnicity data, assessed across the four surveillance domains: 1) case surveillance data, 2) laboratory report data, 3) vaccine administration data, and 4) syndromic surveillance data. Notably, respondents did not perceive that laws, regulations, and policies were prominent barriers to obtaining race and ethnicity data. This finding could help to dispel the misperception that healthcare providers, laboratories, and other mandated reporters are not legally allowed to share race and ethnicity data with public health agencies.



Table 1

Identifying the most common factors that limit STLT public health agencies from obtaining more complete race and ethnicity data for COVID-19. Respondents were allowed to select multiple factors within each surveillance domain.

Assessed Factors	Case Surveillance Data (n = 39)	Laboratory Report Data (n = 40)	Vaccine Administration Data (n = 41)	Syndromic Surveillance Data (n = 25)
Legal barriers (e.g., policy, law, or regulation) that explicitly prohibit, limit, or suppress collection of race & ethnicity data within your state.	3%	5%	5%	4%
Information system limitations.	36%	50%	49%	68%
Insufficient guidance, requirements, or standards for collection and coding.	36%	40%	39%	48%
Limited resources or staffing at the public health agency.	54%	43%	44%	32%
Reporters not providing data for various reasons.	90%	95%	88%	96%
Patient hesitation to indicate their race & ethnicity at point of data collection.	72%	60%	66%	72%
Unsure	3%	3%	2%	4%

In addition to identifying factors that may limit the flow of race and ethnicity data to public health, the assessment also sought to identify what approaches or solutions jurisdictions perceived as helpful for mitigating those factors, both those already implemented and future opportunities to pursue. Respondents were asked to select which approaches they had implemented within their jurisdiction that had already facilitated more complete race and ethnicity data for COVID-19 (experientially helpful) and what approaches they had not yet implemented, but that they felt would be beneficial to facilitate more complete data reporting (hypothetically helpful). **Table 2** describes the percentage of respondents who indicated that a proposed solution would be helpful, delineated by surveillance domain. Very few jurisdictions voiced a perception that there were no possible approaches or solutions that would be helpful for improving the state public health reporting of race and ethnicity for COVID-19.

Table 2 | Perceived helpfulness of potential solutions for facilitating more complete race and ethnicity data for COVID-19 across the queried surveillance domains.

Solution	Surveillance Domain	Experientially Helpful	Hypothetically Helpful
Financial incentives for reporters.	Case surveillance data	2%	38%
	Laboratory report data	7%	47%
	Vaccine administration data	9%	47%
	Syndromic surveillance data	2%	36%
More guidance and education on the benefits of reporting more complete race & ethnicity data.	Case surveillance data	73%	20%
	Laboratory report data	71%	22%
	Vaccine administration data	67%	24%
	Syndromic surveillance data	29%	24%
Information system improvements.	Case surveillance data	36%	36%
	Laboratory report data	40%	33%
	Vaccine administration data	51%	40%
	Syndromic surveillance data	20%	24%
More inclusivity in race & ethnicity response options and ability to store multiple responses.	Case surveillance data	31%	29%
	Laboratory report data	24%	36%
	Vaccine administration data	33%	31%
	Syndromic surveillance data	9%	29%
Changes to state requirements.	Case surveillance data	18%	36%
	Laboratory report data	20%	38%
	Vaccine administration data	13%	42%
	Syndromic surveillance data	2%	36%
Requirements by HHS not already identified above, including by CMS CLIA.	Case surveillance data	13%	24%
	Laboratory report data	36%	27%
	Vaccine administration data	11%	31%
	Syndromic surveillance data	2%	24%
Unsure	Case surveillance data	0%	11%
	Laboratory report data	0%	9%
	Vaccine administration data	2%	11%
	Syndromic surveillance data	2%	9%
No approaches or changes would facilitate more complete race & ethnicity data for COVID-19.	Case surveillance data	2%	4%
	Laboratory report data	2%	7%
	Vaccine administration data	2%	7%
	Syndromic surveillance data	4%	9%

Note: “Experientially Helpful” is defined as a solution that has already been implemented that facilitated more complete race & ethnicity data for COVID-19. “Hypothetically Helpful” is defined as a solution that has not yet been implemented, but would facilitate more complete race & ethnicity data, if implemented.

The Role of Reporting Mandates on Completeness of Race and Ethnicity Data

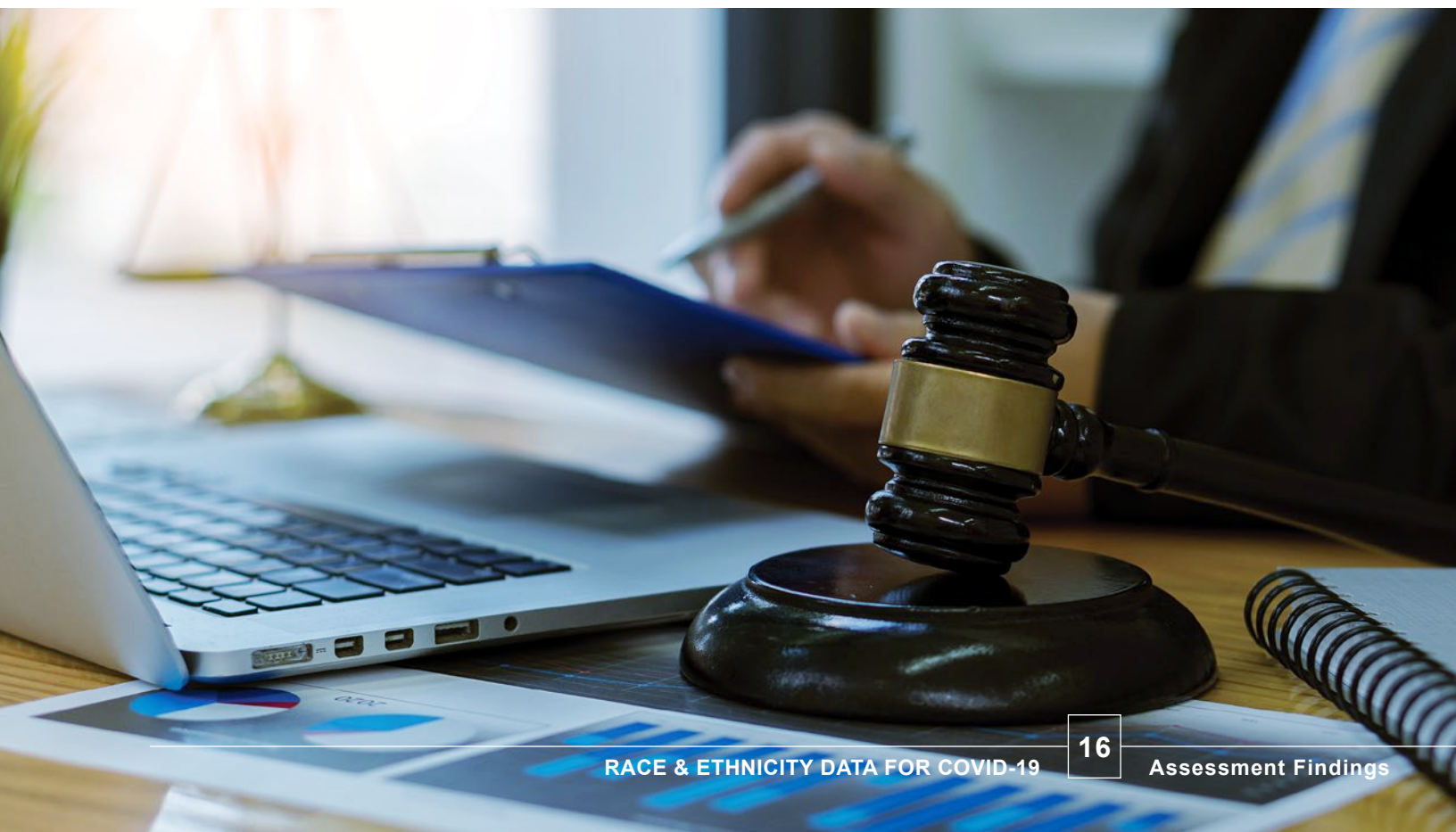
At the time of the assessment, many jurisdictions had already implemented a State or local law, rule, or regulation that explicitly requires reporting race and ethnicity data for COVID-19 to the public health agency. By data source, 67% of jurisdictions had implemented a reporting mandate specifically for laboratory report data, 62% of jurisdictions for case surveillance data, and 47% for vaccine administration data. Fewer jurisdictions (11%) have implemented similar mandates for syndromic surveillance data.

Similarly, federally mandated per the CARES Act¹¹, all laboratories, testing locations, and other facilities or locations performing SARS-CoV-2 testing are required to report data to public health – including both patient race and patient ethnicity. The HHS reporting requirement for laboratories had been enacted for nearly a year at the time of the assessment¹². However, 89% of jurisdictions indicated that there were still outstanding factors affecting their ability to obtain race and ethnicity data from laboratory reports, and at the national level race and ethnicity are only complete in 29% of COVID-19 electronic laboratory reports.

What is the true impact of these reporting mandates on the completeness and quality of race and ethnicity data reported to public health for COVID-19? While both State and federal mandates can be useful tools to facilitate reporting, it is evident that requirements alone are insufficient. Rather, it is necessary to explore systemic factors contributing to the gaps in race and ethnicity data – including where in the reporting stream these factors arise – in order to implement targeted, effectual, and well-resourced solutions.

¹¹ Public Law 116-136, § 18115(a), the Coronavirus Aid, Relief, and Economic Security (CARES) Act, requires “every laboratory that performs or analyzes a test that is intended to detect SARS CoV-2 or to diagnose a possible case of COVID-19” to report the results from each such test to the Secretary of the Department of Health and Human Services (HHS). Congress. HR 748 – CARES Act. <https://www.congress.gov/bills/116/congress/house-bills/748> (Accessed Sept. 6, 2021).

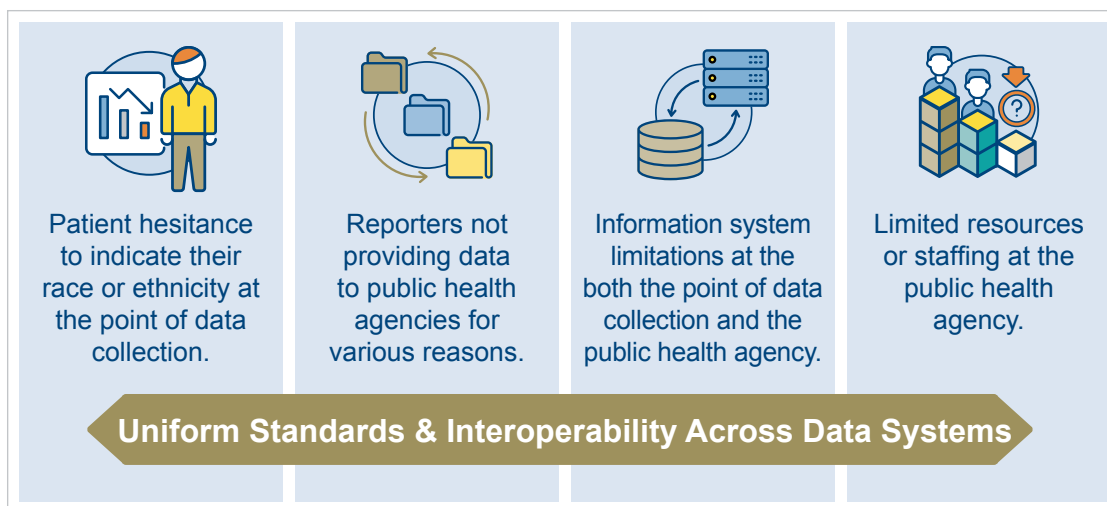
¹² The HHS laboratory reporting guidance was issued pre-emptively on June 4, 2020 and the requirement officially took effect on August 1, 2020.



Digging Deeper

Further Exploration of Assessed Factors and Solutions for Public Health Reporting of Race and Ethnicity Data for COVID-19

Many of the identified factors and potential solutions are intertwined and have cascading effects on data quality and utility, and of note frequently occur upstream of the state or local public health agency – typically at the point of data collection. This report organizes and further explores these findings within four thematic domains, underscored by a crosscutting need for uniform standards and interoperability across data systems.



Patient hesitance to indicate their race or ethnicity at the point of data collection.

Respondents identified patient hesitance to indicate their race & ethnicity at point of data collection as a leading factor that impacted their ability to acquire complete race and ethnicity data across all assessed surveillance domains:

- **72%** of respondents identified as a limiting factor within **case surveillance data**.
- **60%** of respondents identified as a limiting factor within **laboratory report data**.
- **66%** of respondents identified as a limiting factor within **vaccine administration data**.
- **72%** of respondents identified as a limiting factor within **syndromic surveillance data**.

Providers, laboratories, vaccine administrators, and other entities interacting with patients cannot report race and ethnicity data to public health if the patient is hesitant or unwilling to provide this information in the first place. Several jurisdictions noted common experiences with individuals refusing to provide their race and ethnicity during medical encounters and emergency department visits, at testing sites, and when receiving the COVID-19 vaccine.

Patient reluctance to disclose these data are multifactorial and often steeped in cultural trauma, fear of discrimination and stigma, and an historical distrust of governmental record-keeping and research. Patients may be unclear on why they are being asked to provide their race and ethnicity and how those data will be used, resulting in a reluctance that can be further exacerbated by the *manner* in which they are being asked, if not done in a culturally sensitive way. Eighty-two percent of jurisdictions indicated that patient reluctance to disclose their race and ethnicity decreases the quality of data reported to their agency.

Alternatively, individuals may be willing to provide this information but do not identify with the race and ethnicity options available to them on data collection forms. Data collection forms often only reference the five minimum categories standardized by the Office of Management and Budget (OMB) for race (American Indian or Alaska Native; Asian; Black or African American; Native Hawaiian or Other Pacific Islander; and White) and the two options for ethnicity (Hispanic or Latino; Not Hispanic or Latino) and may not allow for the selection of multiple options. Patients that report something different from the available choices are often captured as “Other.” Jurisdictions conveyed that these minimum standards are often insufficient to meet the needs of their local populations. Lack of accurate representation within race and ethnicity categories can lead patients to decline to answer, or to simply be captured or recategorized as “Other,” which has limited utility for informing public health action.

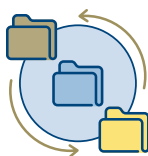
There are no fast-track solutions to remedy the lasting effects of institutionalized racism that contribute to patient reluctance to indicate their race or ethnicity; however, there may be more immediate opportunities to improve how these important data are requested and collected. When asked what solutions would be either experientially or hypothetically helpful to facilitate more complete race and ethnicity data for COVID-19:

EDUCATION AND GUIDANCE

- 73% of respondents indicated that the provision of **more education and guidance on the benefits of reporting** more complete data to public health have already proven fruitful for improving completeness within case surveillance data, 71% for laboratory report data, 67% for vaccine administration data, and 29% for syndromic surveillance.
- About a fifth of respondents had not yet provided additional education and guidance to partners on the benefits of reporting race and ethnicity data – but noted that it would be helpful across all surveillance domains if implemented.
- Guidance could emphasize the importance of reporting data to public health, including how public health ultimately uses the data to illuminate inequities and inform action, explain the benefits to healthcare for collecting this information for their own use, and provide additional training for requesting and collecting these data from patients in a respectful, intentional, and culturally appropriate way. There is still need for further discussion on who would develop such educational materials and guidance, to whom specifically that information would be targeted, and the role of public health in educating the target audience. In any regard, it is essential that community and cultural leaders be engaged in this effort.

EXPANDING INCLUSIVITY OF RACE AND ETHNICITY RESPONSE OPTIONS

- For improving completeness within vaccine administration data, 33% of respondents indicated that **implementing more inclusivity in response options for race and ethnicity data and allowing the option to select multiple options on data collection forms** yielded some success already (31% for case surveillance data and 24% for laboratory report data).
- A comparable 31% of respondents indicated that re-evaluating values sets to be more inclusive would be hypothetically helpful for improving completeness of race and ethnicity data within vaccine administration data (36% for case surveillance data and 29% for laboratory report data). Only 9% of respondents had already implemented more inclusive value sets at the healthcare facility for syndromic surveillance, however 29% perceived this solution would be similarly facilitate improved completeness within syndromic surveillance data, if implemented.
- Expanded response options for race and ethnicity at the point of data collection and within value sets for utilization at the state and local level should be standardized across all conditions and be able to be accurately mapped to the minimum OMB standards.



Reporters **not** providing data to public health agencies for various reasons.

Respondents identified that reporters not providing data to public health significantly impacted their ability to acquire complete race and ethnicity data across all assessed surveillance domains:

- **90%** of respondents identified as a limiting factor within **case surveillance data**.
- **95%** of respondents identified as a limiting factor within **laboratory report data**.
- **88%** of respondents identified as a limiting factor within **vaccine administration data**.
- **96%** of respondents identified as a limiting factor within **syndromic surveillance data**.

Qualitative responses revealed that providers, laboratories, vaccine administrators, and other entities required to report to public health fail to do so for numerous reasons. It is germane to reiterate that the target audience for the assessment was State Epidemiologists or delegated staff at state and local health departments, and therefore these perceived factors and solutions were identified unilaterally by public health – not directly by mandated reporters. Further assessment of reporters is warranted in order to understand the full spectrum of viewpoints and challenges regarding collecting and reporting race and ethnicity data for COVID-19.

Frequently, when mandated reporters do not report race and ethnicity data to public health it is because the data do not exist within their information management systems. Lack of data within information systems may occur for various reasons, including:

- While patient reluctance to self-report their race and ethnicity certainly contributes to this missingness, some jurisdictions indicated a discomfort or hesitance on the part of the provider or contact investigator to even solicit this information from the patient.
- In some cases, data collection or intake forms do not contain fields to systemically capture race and ethnicity data in a standardized format. Even if these fields are present on data collection forms, providers, registration clerks, or triage nurses may not always capture self-reported race and may instead assign a race and ethnicity based on assumptions made about the patient related to appearance, last name, or other factors.
- Lastly, surges of COVID-19 have had incapacitating effects on our healthcare infrastructure. During these periods of high patient volume, overwhelmed healthcare providers, emergency departments, vaccination and testing sites may not view asking for patient race and ethnicity as a priority if it does not acutely contribute to a clinical diagnosis or producing a test result.

Several jurisdictions specifically called out incomplete race and ethnicity data for COVID-19 within laboratory report data. Sustained public health dedication to rigorous and routine testing for SARS-CoV-2 ensures that laboratories and the data they provide to public health will continue to play a pivotal role throughout the pandemic. Identification and enumeration of COVID-19 cases have been largely driven by laboratory testing, and a positive test result may be the only indication to trigger a case report to public health. Laboratories often state that they cannot report race and ethnicity data to public health because they do not receive the data on test orders and forms submitted by providers and testing site personnel. On the other hand, some laboratories may receive the data, but the laboratory information management system is not enabled to capture and store the data. Finally, newer and non-traditional testing facilities (e.g., mobile testing vans, pop-up sites) may be unfamiliar with how and what to report to public health, requiring extensive onboarding from public health agencies to get the data flowing – either manually or electronically.

Jurisdictions perceived a general lack of awareness among traditional and non-traditional reporters alike that these fields are required elements for reporting. And in some scenarios such as surges in cases and hospitalizations, even if the importance and requirements for reporting race and ethnicity data to public health are well understood, facilities are functionally unable due lack of staff and resources to collect and report the data.

Jurisdictions identified the following solutions for mitigating these barriers:

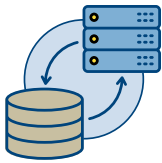
EDUCATION AND GUIDANCE

- A crosscutting solution, **more education and guidance on the benefits of reporting** was noted as a successful approach for increasing awareness on the importance of collecting and reporting race and ethnicity data to public health. Letters, webinars, health alerts, and consistent messaging from governmental leaders were identified as mechanisms to provide this information.
- For laboratory reporting, jurisdictions noted gains in leveraging the onboarding process as an opportunity to provide training on collecting race and ethnicity data and sending to public health using current Health Level Seven International (HL7) standards¹³. For syndromic surveillance, users from reporting facilities were provided with guidance, including the provision of mapped values from local codes to national standards.
- Some jurisdictions convene regular webinars that report out on case surveillance, laboratory, and vaccine administration data by race and ethnicity. **Illustrating the real impact of the data and how they are used to identify disparate outcomes and drive resources to certain areas is an essential connection to make in order to improve reporting.** Targeting this outreach to high-volume reporters with missing data could provide a comparatively large return on investment.
- Providing guidance, training, webinars, and onboarding support to reporters requires considerable staffing and resources. Funding and hiring support must be considered in order to support these activities. It is also prudent for this guidance to be developed and shared nationally to emphasize the collective messaging on the importance of race and ethnicity data for COVID-19.

FINANCIAL INCENTIVES FOR REPORTING

- Less than 10% of respondents indicated they currently offer additional incentivization for reporting these data. However, many respondents indicated that **tying financial incentives to public health reporting of race and ethnicity data** could hypothetically improve data completeness across all surveillance domains. Incentivization should focus on completeness of reported data, as well as reporting data in a manner consistent with local, state, and national standards.
- Incentives may appear in form of mini grants or federal funding to modernize and maintain computer systems to enable sending relevant data to public health, including routine system updates to align with evolving health information technology standards. The Centers for Medicare and Medicaid Services (CMS) Promoting Interoperability Program is another method to apply incentives to health care institutions and electronic health record vendors to improve the completeness of standardized race and ethnicity data and to automate their transmission to laboratories and public health.
- Electronic case reporting (eCR) provides a transformative opportunity to improve public health reporting while reducing the manual burden for providers to report. Incentives to implement eCR could ease and clarify the reporting process for providers and high-volume healthcare systems. CMS recently added a requirement in their Promoting Interoperability Program to require eligible hospitals to participate in eCR beginning in 2022.
- Local public health agencies stressed that such incentives would likely need to come from the state or federal level.

¹³ HL7 is a non-profit organization that supports development of standards for the exchange, integration, and sharing of electronic health information.



Information system **limitations** at the both the point of data collection and the public health agency.

Incomplete or inaccurate race and ethnicity data at STLT public health agencies is often a byproduct of insufficient capability of information systems to capture and store the data. Respondents indicated that information system limitations both at the point of data collection as well as at the public health agency had profound impacts of completeness of race and ethnicity data for COVID-19 across all queried surveillance domains:

- **36%** of respondents identified as a limiting factor within **case surveillance data**.
- **50%** of respondents identified as a limiting factor within **laboratory report data**.
- **49%** of respondents identified as a limiting factor within **vaccine administration data**.
- **68%** of respondents identified as a limiting factor within **syndromic surveillance data**.

For syndromic surveillance, at the point of data collection hospital information systems may be unable to store race and ethnicity data elements, or may only be able to store one response, resulting in capturing patients that report multiple races as “Other.” Similarly, syndromic surveillance systems at the public health agency cannot always capture and store multiple race and ethnicity categories, inaccurately recategorizing multiracial selections as “Other.” These re-classifications decrease the utility of the data for public health. Syndromic surveillance systems can also be prohibitively particular in their ability to interpret only correctly labeled codes for race and ethnicity, requiring public health agency staff to re-code the data for any hospitals that send non-standard codes – an arduous task affecting both staff resources and database processing capabilities.

For laboratory report and vaccine administration data, information system limitations often accompany a lack of intentional processes to capture complete race and ethnicity data at the point of data collection, or failure to do so in a standardized way. Laboratory information management systems (LIMS) are typically built to capture the data necessary to complete the laboratory test and return results to the ordering provider, and to meet minimal requirements for reporting to the appropriate public health authority. Laboratories that service multiple jurisdictions may find it difficult to configure their LIMS to balance multiple sets of standards and requirements for collecting and transmitting race and ethnicity data to public health. In return, even though race and ethnicity are technically required for laboratories to report, multiple jurisdictions relayed that they prefer to receive an incomplete message from laboratories (whether via HL7 or other electronic mechanism) rather than potentially delay the message to ensure all required fields are complete. In short, validation processes are relaxed to ensure the message does not fail if it does not include race or ethnicity. Given the unprecedented demands and requested frequency and timeliness for STLT public health agencies to report these data for national aggregation, this practice is not entirely surprising. Similar to syndromic surveillance data, any race and ethnicity data that a laboratory reports using local or non-standard codes must be re-coded by the public health agency to standard values. Regarding vaccination data for COVID-19, immunization information systems (IIS) also have inconsistent or altogether absent requirements for capturing race and ethnicity. Race and ethnicity may not be required data fields or even present within the IIS, and therefore providers and vaccine administrators do not request the information when interacting with the patient. There are inconsistent standards and guidance in how race and ethnicity data for COVID-19 should be collected within the immunization information system, resulting in variable system capabilities and configurations across jurisdictions. At least one jurisdiction noted differing specifications across the different immunization surveillance systems *within their own state*.

A common theme regarding information system limitations across all surveillance domains is the lack of interoperability and access between data systems. Even if race and ethnicity data are captured at the point of data collection, each “leap” between information systems presents a possible crack for the data to fall through. Lack of interoperability is further exacerbated by inconsistent application of standards within data systems, including unclear mapping and adjudication procedures. The end result is often that data do not transfer well between systems and may be inaccurately transformed or refactored – the meaningfulness of the data ultimately becomes lost in translation.

Updates to information systems require significant and sustained investment across the entire health ecosystem, including from federal and STLT public health agencies, healthcare, laboratories, and the vendor community for health information systems (e.g., LIMS, IIS, EHR, and surveillance systems). Acknowledging this requisite investment, respondents identified the following solutions to address the current limitations of information systems, including opportunities for automated matching to additional databases to obtain missing race and ethnicity data.

IMPROVING INFORMATION SYSTEMS

- 51% of jurisdictions have implemented changes to their immunization surveillance systems and vaccine registries to improve the completeness and accuracy of race and ethnicity data. These modifications include **making race and ethnicity required data elements** to capture within the vaccination database, **allowing selection and consumption of multiple responses**, and re-positioning race and ethnicity fields on data collection forms to be located nearer to other, more consistently collected demographic data such as name and age. Some jurisdictions have also required that race and ethnicity be completed at the time of vaccine registration, instead of at the time of vaccine administration.
- 40% of jurisdictions have made similar system improvements for laboratory information management systems, including specifying race and ethnicity as required fields for transmission and processing of electronic messages. Where resources allow, public health agencies may evaluate the completeness of race and ethnicity data submitted by laboratories and provide feedback to submitters.
- For improving completeness within case surveillance and syndromic surveillance data, respondents experienced gains in working directly with EHR vendors to improve collection of race and ethnicity and requesting that hospitals add these fields when upgrading their data systems. Prospectively, guidance should be updated to explicitly state that race and ethnicity are required data elements, though patients should be allowed to decline to answer.
- Data collection systems were also configured to accept “Prefer not to specify race or ethnicity” as a valid response to enable public health to discern if the patient declined to answer as opposed to a missing or blank response.
- Respondents emphasized that **reporters need funding and incentives to create, modify and maintain data systems to capture race and ethnicity data**, particularly within electronic health records or laboratory information systems given the data are not essential for core functions of clinical diagnosis or performing the test.

LEVERAGING ADDITIONAL DATA SOURCES FOR AUTOMATED MATCHING AND VALIDATION OF RACE AND ETHNICITY DATA

- Respondents indicated that health information exchanges (HIEs) and master patient index would be the most helpful data sources to leverage for automated matching and validation to improve the completeness and quality of race and ethnicity data. However, 29% of respondents also indicated their agency did not have access to a master patient index. Nonetheless, for those that are able, **jurisdictions are encouraged to implement and use a master patient index as an opportunity to tap into patient information collected across multiple data sources.**
- Driver registration data is somewhat helpful and potentially worth pursuing for some, although various respondents noted that race and ethnicity information is not captured by their Department of Motor Vehicles, and 29% indicated they were unable to access these data.
- While some respondents noted that LexisNexis could be useful, many respondents (36%) were unsure of the utility of LexisNexis for their jurisdiction's needs.
- **Matching to additional data sources, if done manually, can be very labor-intensive for data managers and should be largely automated.** Tailored technical assistance on how jurisdictions could leverage these databases would be beneficial for filling in gaps in missing race and ethnicity data for COVID-19.
- In select situations where there are sufficient race and ethnicity and other demographic data to support imputation, **the process of imputation should be considered as an adjunct method to improve completeness** – but should not replace attempts to improve completeness of race and ethnicity data collected by self-report, interview, or electronic health records.

UNIFORM STANDARDS AND INTEROPERABILITY ACROSS DATA SYSTEMS

- Where universal standards for collecting and coding race and ethnicity data are not yet available, such as for immunization surveillance systems or vaccine registries, uniform and inclusive standards should be developed. **Public health agencies should make a commitment to adopt these standards within their own surveillance systems.** Further guidance on existing and forthcoming standards should be provided to public health agencies and reporters alike.
- Increased data standardization and compliance from reporters will yield smoother interoperability between data systems, reducing the burden on STLT public health agency staff to re-code or map responses.



Limited resources or staffing at the public health agency, exacerbated by all of the above.

Respondents indicated that limited resources or staffing at the public health agency affects the completeness of race and ethnicity data for COVID-19 across all assessed surveillance domains:

- **54%** of respondents identified as a limiting factor within **case surveillance data**.
- **43%** of respondents identified as a limiting factor within **laboratory report data**.
- **44%** of respondents identified as a limiting factor within **vaccine administration data**.
- **32%** of respondents identified as a limiting factor within **syndromic surveillance data**.

When race and ethnicity are incomplete on case report forms, laboratory reports, and within vaccine administration records, STLT public health agencies must conduct time-intensive outreach to obtain these missing data. Staff must also reconcile discrepant responses for the same individual across multiple records or data systems. Seventy-one percent of respondents noted that such discrepancies ultimately reduce the quality of the race and ethnicity data they receive. For data sources that are high-data-volume and low-data-completeness, such as laboratory report data, the task to follow up can seem insurmountable.

Patient hesitance to indicate their race and ethnicity, reporters not providing data for various reasons, and information system limitations collectively contribute to the strain on public health agency staffing and resources – culminating in gaps in the completeness and accuracy of race and ethnicity data for COVID-19 available at the STLT public health agency. Many jurisdictions do not have the staffing needed to educate reporters, onboarding facilities, map local responses to standardized codes, or interview cases for blank or unknown responses.

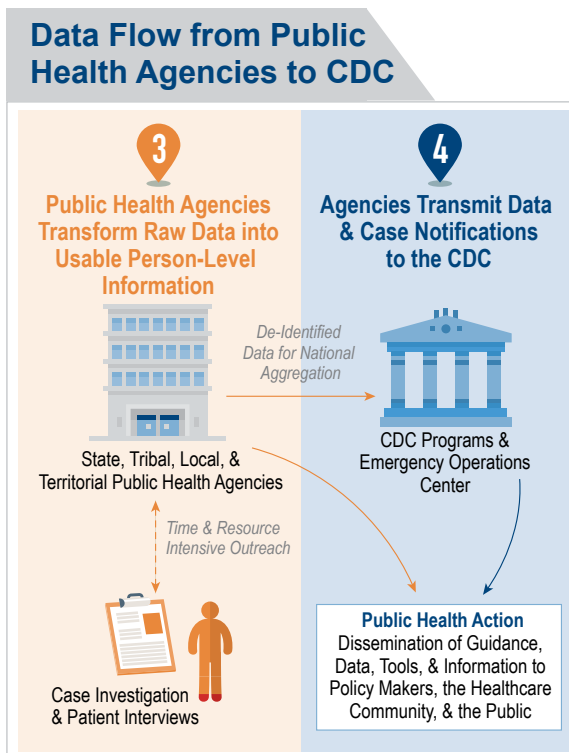
Flexible funding and sustained investments in our public health workforce will yield immeasurable returns as we strive to modernize and maintain mechanisms for public health reporting.

At the National Level

Race and Ethnicity Data Sent from the State, Territorial, and Local Public Health Agency to the CDC.

In addition to identifying upstream factors that impact the completeness and quality of race and ethnicity data at the STLT public health agency, respondents were also asked if there were factors that affected their agency's ability to send all obtained race and ethnicity for COVID-19 data onward to the CDC. **The vast majority of respondents (67%) send all the race and ethnicity data for COVID-19 they have from each surveillance domain (case surveillance data, laboratory report data, vaccine administration data, and syndromic surveillance data) to the CDC.** Of the 15 jurisdictions that do not send all obtained race and ethnicity data to the CDC, respondents cited the following factors:

- Three jurisdictions indicated limitations to sending all race and ethnicity within their COVID-19 case surveillance data to the CDC. Jurisdictions cited information system issues and limited resources or staffing at the public health agency as the prominent factors impacting data transmission.
- Similarly, three jurisdictions noted limitations in sending all race and ethnicity data obtained from laboratory report data, due to information system issues.
- Eight jurisdictions noted limitations to sharing all acquired race and ethnicity data within their COVID-19 vaccine administration data. In contrast to the technical and staffing barriers that were implicated for case surveillance and laboratory report data, the most prevalent reasons for reduced sharing of these data nationally were related to state laws or agency policies that limit or prohibit further sharing of race & ethnicity data for COVID-19.
- Relatively little was known regarding the factors impacting the ability to send all race and ethnicity data obtained from syndromic surveillance data.

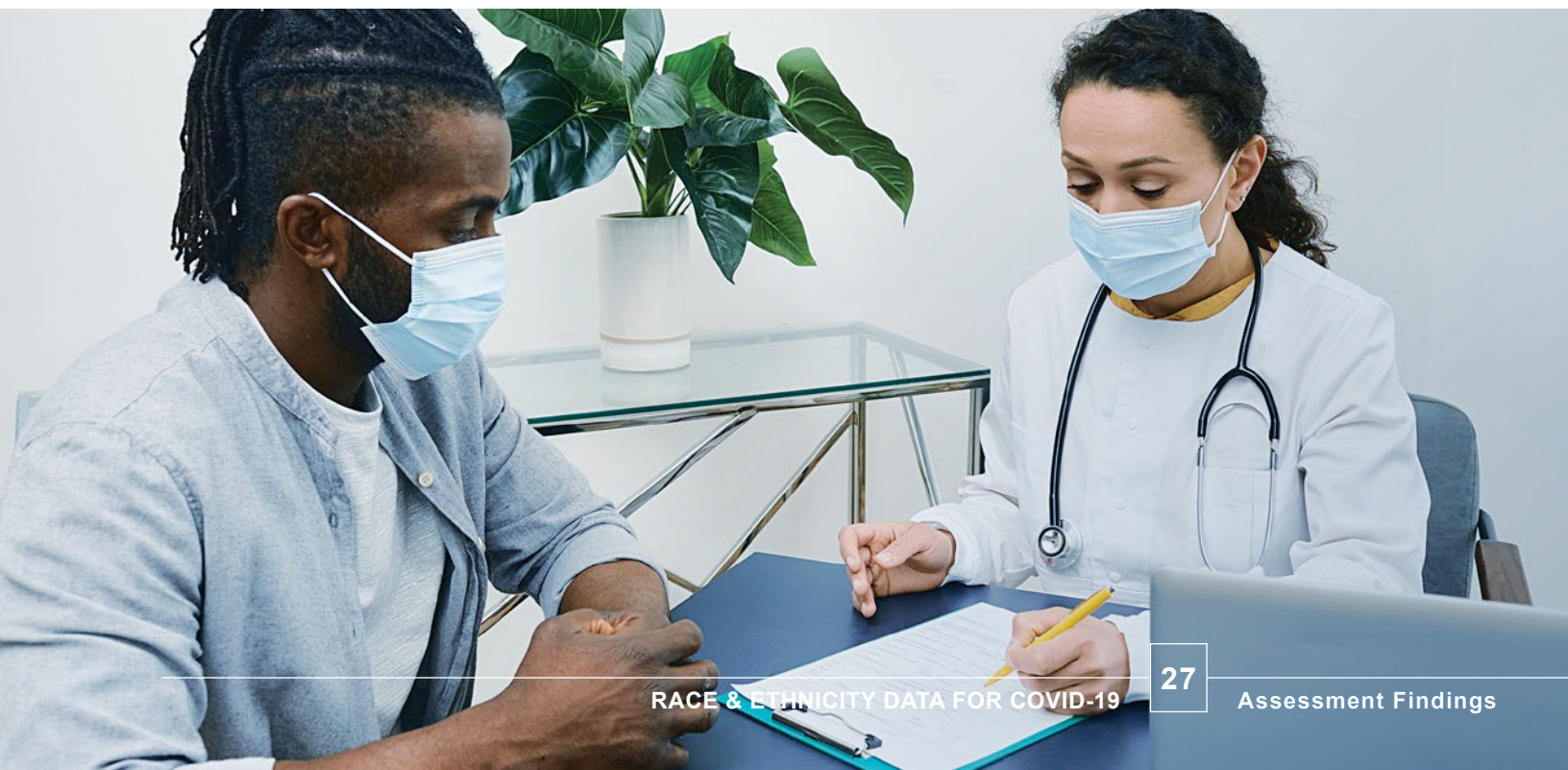


These findings reaffirm that many of the factors contributing to observed gaps in race and ethnicity data for COVID-19 within national data sets are occurring at the point of data collection and consumption.

Limitations

This assessment provides key insight into the challenges that public health agencies face in obtaining epidemiologically meaningful race and ethnicity data for COVID-19. However, several limitations must be acknowledged:



- The target respondent audience for the assessment was State Epidemiologists and delegated staff at state, local, and territorial public health agencies. Many of the factors impacting public health reporting of race and ethnicity data identified by respondents occur at the point of data collection (e.g., patient's willingness to disclose their race and ethnicity), including at hospitals, healthcare facilities, laboratories, testing sites, and other settings. Personnel in these settings were not directly assessed. Further assessment targeted towards these partners is recommended in order to understand the full spectrum of viewpoints and challenges regarding collecting and reporting race and ethnicity data for COVID-19 –including exploring the impact of patient reluctance to self-report their race and ethnicity versus provider reluctance to ask for this information.
- The scope of this assessment was intentionally exploratory and high-level; therefore, certain nuanced details may have not been captured. Findings and recommendations included within this report are intended as a jumping off point for subsequent, in-depth examination of the factors and solutions identified by respondents.
- The response rate was adequate for States (72%), yet relatively low for large local public health agencies (30%) and territories (13%). Additionally, small- or mid-sized local health agencies and tribal epidemiology centers (TECs) were not directly assessed. A similar assessment directed toward all local public health agencies and more targeted outreach to territories and TECs would help illuminate the similar and unique challenges that these public health agencies encounter when obtaining race and ethnicity data for COVID-19 and provide more granular insight on the specific populations they serve.



RECOMMENDATIONS

Assessment respondents from public health agencies identified several factors that impact the completeness and quality of race and ethnicity data for COVID-19 that they are able to obtain from healthcare providers, laboratories, vaccine administrators, and other reporting entities. CSTE thoughtfully considered the identified factors and solutions, and in response developed the following recommendations for improving gaps in public health reporting of these critical demographic data. **Table 3** summarizes these recommendations, including information on which factor is being addressed, solution themes, and recommendations for mitigation. Efforts to alleviate these factors at their source will empower reporters and state, territorial, local, and tribal public health agencies to comply with reporting requirements and effectively translate into more meaningful and available race and ethnicity data at both the local and national level.

Table 3 Recommendations to mitigate factors affecting public health reporting of race and ethnicity data for COVID-19.

Identified Factor	Recommendation for Mitigation
 <p>1 Patient Hesitance to Indicate Their Race or Ethnicity at the Point of Data Collection</p>	<p>Expanding Inclusivity of Race and Ethnicity Value Sets Uniform Standards and Interoperability Across Data Systems</p> <p>A. Evaluate current race & ethnicity data collection specifications across jurisdictions and identify opportunities to expand response options and value sets, including codes to delineate “Unknown” vs “Patient Refused to Answer.”</p> <hr/> <p>Education and Guidance</p> <p>B. Convene representatives from public health, providers, health equity advocacy groups, interpreters, and other relevant stakeholders to discuss historical context and patient concerns regarding collection of race & ethnicity data. Consider convening regularly to discuss ongoing challenges and solutions for collecting and reporting race & ethnicity data, and to demonstrate the real-world impacts of utilizing the data.</p> <p>C. Develop trainings and guidance for healthcare providers, test site personnel, vaccine administrators, contact tracers, and other staff on how to request race & ethnicity data from patients in a culturally appropriate way.</p>
 <p>2 Providers and Laboratories Not Providing Race and Ethnicity Data for COVID-19 for Various Reasons</p>	<p>Education and Guidance Uniform Standards and Interoperability Across Data Systems</p> <p>A. Develop educational materials including trainings, webinars, and handouts with input from relevant communities that:</p> <ol style="list-style-type: none"> 1. Address provider discomfort or hesitation to solicit race and ethnicity information from the patient. Providers include frontline medical workers, frontline staff (e.g., administrative, clerical, reception, and Emergency Department admission & triage staff), ancillary providers, contact investigators, schools, pharmacies, labs, etc. 2. Emphasize the importance of collecting and reporting race & ethnicity data. 3. Outline how public health uses the data for response, and how the data are also beneficial for healthcare. 4. Link to additional resources and information on how to collect and report race & ethnicity data to public health using the appropriate standards.


Continued on page 29

Table 3 Recommendations to mitigate factors affecting public health reporting of race and ethnicity data for COVID-19. *continued from page 28*

Identified Factor	Recommendation for Mitigation
<p>2 Providers and Laboratories Not Providing Race and Ethnicity Data for COVID-19 for Various Reasons</p>	<p>Information System Improvements Uniform Standards and Interoperability Across Data Systems</p> <p>B. Define race & ethnicity as required fields in data collection forms and systems and allow collection and storage of multiple values. Associated guidance should explicitly specify race & ethnicity as required, however missing data should not cause the message to automatically fail. Validation measures and warning messages to identify missing race and ethnicity data and prompt for entry could be a technical solution to encourage compliance with the requirement without disrupting work or data flows.</p> <p>C. Create standardized specifications for collection and mapping of race & ethnicity data, including for immunization surveillance systems and registries.</p> <p>D. Encourage jurisdictions to implement a universal set of standardized specifications for the collection of race & ethnicity data from reporters.</p> <p>E. Require providers and other test order submitters to complete race & ethnicity upon order of COVID-19 lab test.</p>
	<p>Financial Incentives for Reporting Information System Improvements</p> <p>F. Assess laboratories to better understand current capability and barriers of information systems to capture, store, and transmit race & ethnicity data.</p> <p>G. Provide technical assistance and funding to ensure laboratory information systems have the capability to capture, store, and transmit multiple values for race & ethnicity data.</p>
	<p>Financial Incentives for Reporting Uniform Standards and Interoperability Across Data Systems</p> <p>H. Incentivize laboratories to implement current Health Level Seven International (HL7) messaging standards to transmit laboratory report data electronically to the public health agency.</p>
	<p>Information System Improvements Build Public Health Workforce Capacity</p> <p>I. Provide technical assistance and dedicated funding to public health agencies to establish and maintain electronic case reporting (eCR) feeds.</p>
	<p>Financial Incentives for Reporting Information System Improvements</p> <p>J. Promote and incentivize adoption of eCR by healthcare providers.</p>
	<p>Financial Incentives for Reporting Uniform Standards and Interoperability Across Data Systems</p> <p>K. Tie provider incentives to reporting of complete race & ethnicity data in a manner consistent with standardized specifications.</p>

Continued on page 30

Table 3 Recommendations to mitigate factors affecting public health reporting of race and ethnicity data for COVID-19. *continued from page 30*

Identified Factor	Recommendation for Mitigation
 <p>3 Information System Limitations</p>	<p>Information System Improvements</p> <p>A. Enable public health surveillance systems to capture and store multiple race and ethnicity values.</p> <hr/> <p>Information System Improvements Uniform Standards and Interoperability Across Data Systems</p> <p>B. Enable all public health surveillance systems to accept HL7 messages.</p> <hr/> <p>Information System Improvements Uniform Standards and Interoperability Across Data Systems</p> <p>C. Explore technologies to centralize mapping and translation of local codes for race & ethnicity into the standardized codes specified by public health agencies.</p> <hr/> <p>Leverage Additional Databases Build Public Health Workforce Capacity Education and Guidance</p> <p>D. Conduct an environmental scan of databases (e.g., driver registration data, LexisNexis, vital records, etc.) to assess completeness and utility of included race & ethnicity data.</p> <p>E. Provide best practices and functional requirements for public health agencies to access databases and perform automated matching to ascertain and validate missing or inconsistent race & ethnicity data.</p> <p>F. Consider the use of imputation as an adjunct method to improve completeness of race & ethnicity data, where there are sufficient race, ethnicity and other demographic data to support imputation. Courses and considerations related to imputation processes should be compiled to assist public health agencies with this approach.</p> <hr/> <p>Information System Improvements Build Public Health Workforce Capacity Education and Guidance</p> <p>G. Provide resources to for public health agencies to develop automated qualitative assurance (QA) tools and dashboards that can generate completeness reports for incoming race & ethnicity data by facility and provider. Generated reports can be used for targeted outreach by public health agency staff and provision back to reporters.</p>
 <p>4 Limited Resources or Staffing at the Public Health Agency</p>	<p>Education and Guidance Uniform Standards and Interoperability Across Data Systems</p> <p>A. Evaluate and provide guidance to public health agencies on best practices for summarizing, compiling, and analyzing race & ethnicity data.</p> <hr/> <p>Build Public Health Workforce Capacity</p> <p>B. Allow flexibility and contracting assistance to hire additional staffing to support data collection, validation, mapping, and management.</p> <hr/> <p>Information System Improvements Build Public Health Workforce Capacity</p> <p>C. Build in sustained and flexible funding for information systems improvements and for hiring, training, and retaining an informatics-competent workforce to maintain information systems.</p>



APPENDIX

Complete Assessment Instrument

Factors & Facilitators Affecting Completeness & Quality of Race/Ethnicity Data for COVID-19