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

Introduction:

The objective of this assessment is to identify and understand factors that affect the meaningfulness of race/ethnicity data obtained for COVID-19 public health action. For the purpose of this brief assessment, meaningful race/ethnicity data are defined as:

- **Complete:** Required fields for race/ethnicity are filled out according to the Office of Management and Budget (OMB) Standards for the Classification of Federal Data on Race and Ethnicity and do not contain a NULL or UNKNOWN value.
- **Accurate:** Obtained data accurately represent the self-identified race/ethnicity of the individual for which the record was made.

Meaningful race/ethnicity data for COVID-19 are both complete and accurate enough to inform public health action.

Survey Contents:

This assessment is divided into two sections:

- **Section 1** focuses on understanding which factors affect the completeness and quality of the race/ethnicity data for COVID-19 that your state or local public health agency obtains from healthcare providers, laboratories, and other mandated reporters.
- **Section 2** focuses on understanding which factors affect your jurisdiction's ability to send obtained race/ethnicity data from your state or local public health agency to the CDC.

Questions within both sections address factors affecting race/ethnicity data across four surveillance domains: 1) Case surveillance data, 2) Laboratory report data, 3) Vaccine administration data, and 4) Syndromic surveillance data.

Intended Respondents:

We anticipate this assessment will require 25 minutes to complete.

CSTE intends for the State Epidemiologist to be the primary respondent to this assessment. Given that questions assess multiple surveillance domains, it may be prudent to coordinate and delegate among additional staff (e.g., Surveillance/Informatics POC, ELR coordinator, COVID-19 immunizations coordinator, etc.), as necessary.

Submission Deadline and Coordination:

We kindly request only one (1) complete assessment response per jurisdiction by **Thursday, May 13th, 2021**.

Please note that respondent demographic information will be used only for internal coordination and follow-up if needed. The resulting summary report and any related presentations will only include de-identified, aggregate data.

If you have any questions while completing this assessment, please contact Brooke Beaulieu (brooke@cste.org) at the CSTE National Office.

Section 1: Completeness of Race/Ethnicity Data for COVID-19 at the State or Local Public Health Agency

This set of questions focuses on understanding which factors affect the completeness and quality of the race/ethnicity data for COVID-19 that your state or local public health agency (PHA) obtains from healthcare providers, laboratories, and other mandated reporters.

Q1. Please provide the following information.

- **Name:** _____
- **Affiliation:** _____
- **Role/Title:** _____
- **Email Address:** _____

Q2. Does your state law, rule, or regulation explicitly require reporting of race/ethnicity data to the public health agency within any of the following surveillance domains? Select all the apply.

- [ ] Yes, for case surveillance data.
- [ ] Yes, for laboratory report data.
- [ ] Yes, for vaccine administration data.
- [ ] Yes, for syndromic surveillance data.
- [ ] No, our state law does not explicitly require reporting of race/ethnicity data.
- [ ] Unsure.

Q3. Are there factors that limit your agency's ability to obtain meaningful race/ethnicity data for COVID-19 within any of the following surveillance domains? Meaningful race/ethnicity data are both complete and accurate enough for public health action. Select all that apply.

- ☐ Yes, for case surveillance data.
- ☐ Yes, for laboratory report data.
- ☐ Yes, for vaccine administration data.
- ☐ Yes, for syndromic surveillance data.
- ☐ We are not currently experiencing any factors that limit our agency's ability to obtain complete race/ethnicity data for COVID-19.
- ☐ Unsure.

>>> IF respondent selects "We are not currently experiencing any factors that limit our agency's ability to obtain complete race/ethnicity data for COVID-19." THEN SKIP to Q6.

All Else, PROCEED to Q4.

Q4. Please use the matrix below to indicate which factors affect your agency's ability to obtain **complete** race/ethnicity data for COVID-19 for each surveillance domain. Select all that apply.

	Case Surveillance Data	Laboratory Report Data	Vaccine Administration Data	Syndromic Surveillance Data
Legal barriers (e.g., policy, law, or regulation) that explicitly prohibit, limit, or suppress collection of race/ethnicity data within your state.	☐	☐	☐	☐
Information system limitations.	☐	☐	☐	☐
Insufficient guidance, requirements, or standards for collection and coding.	☐	☐	☐	☐
Limited resources or staffing at the public health agency.	☐	☐	☐	☐
Reporters not providing data for various reasons.	☐	☐	☐	☐
Patient hesitance to indicate their race/ethnicity at point of data collection.	☐	☐	☐	☐
Other factors.	☐	☐	☐	☐
Unsure	☐	☐	☐	☐

>>> IF none selected in matrix in Q4, THEN SKIP to Q6.

All Else, PROCEED to Q5.

Q5. [Will only carry forward responses selected in Q4] Is there additional information or detail that you would like to provide for any of the selected factors?

Legal barriers (e.g., policy, law, or regulation) that explicitly prohibit, limit, or suppress collection of race/ethnicity data within your state.	
Information system limitations	
Insufficient guidance, requirements, or standards for collection and coding.	
Limited resources or staffing at the public health agency.	
Reporters not providing data for various reasons.	
Patient hesitance to indicate their race/ethnicity at point of data	
Other factors.	
Unsure.	

Q6. For each surveillance domain, please use the matrix below to indicate the approaches or changes that you *have already implemented* that have facilitated more **complete** race/ethnicity data for COVID-19 in your jurisdiction. Select all that apply.

	Case Surveillance Data	Laboratory Report Data	Vaccine Administration Data	Syndromic Surveillance Data
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/ethnicity value sets and ability to store multiple values.	☐	☐	☐	☐
Changes to state requirements.	☐	☐	☐	☐
Requirements by HHS not already identified above, including by CMS CLIA.	☐	☐	☐	☐
Other changes or approaches.	☐	☐	☐	☐
Unsure	☐	☐	☐	☐
We have not implemented any of these approaches or changes.	☐	☐	☐	☐

>>> IF none selected in matrix in Q6, THEN SKIP to Q8.

All Else, PROCEED to Q7.

Q7. [Will only carry forward responses selected in Q6] Is there additional information or detail that you would like to provide for any of the selected changes or approaches?

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/ethnicity value sets and ability to store multiple values.	
Changes to state requirements.	
Requirements by HHS not already identified above, including by CMS CLIA.	
Changes to state requirements.	
Other changes or approaches.	
Unsure.	
We have not implemented any of these approaches or changes.	

Q8. For each surveillance domain, please use the matrix below to indicate the approaches or changes that *you have not already implemented,* but that would facilitate more **complete** race/ethnicity data for COVID-19 in your jurisdiction *if implemented*. Select all that apply.

	Case Surveillance Data	Laboratory Report Data	Vaccine Administration Data	Syndromic Surveillance Data
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/ethnicity value sets and ability to store multiple values.	☐	☐	☐	☐
Changes to state requirements.	☐	☐	☐	☐
Requirements by HHS not already identified above, including by CMS CLIA.	☐	☐	☐	☐
Other changes or approaches.	☐	☐	☐	☐
Unsure	☐	☐	☐	☐
No approaches or changes would facilitate more complete race/ethnicity data for COVID-19.	☐	☐	☐	☐

>>> IF none selected in matrix in Q8, THEN SKIP to Q10.

All Else, PROCEED to Q9.

Q9. [Will only carry forward responses selected in Q8] Is there additional information or detail that you would like to provide for any of the selected changes or approaches?

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/ethnicity value sets and ability to store multiple values.	
Changes to state requirements.	
Requirements by HHS not already identified above, including by CMS CLIA.	
Changes to state requirements.	
Other changes or approaches.	
Unsure.	
No approaches or changes would facilitate more complete race/ethnicity data for COVID-19.	

Q10. What factors affect the **quality** of the race/ethnicity data that is obtained by your state or local PHA? Select all that apply.

- [ ] Inaccurate or insufficient categories for collecting race/ethnicity data.
- [ ] Information systems are unable to store multiple race/ethnicity options.
- [ ] Receiving non-standardized data.
- [ ] Discrepancies or discordance in race/ethnicity across separate records for the same individual.
- [ ] Patient chooses not to disclose race/ethnicity.
- [ ] Limited resources or staffing at the public health agency to validate race/ethnicity data.
- [ ] Other factors. (*Please describe in space provided.*)
- [ ] We are not currently experiencing any factors that affect the quality of race/ethnicity data we obtain for COVID-19.

Q11. The matrix below contains data sources that could potentially be leveraged for automated matching and validation to improve the completeness and quality of race/ethnicity data. Please rate each data source based on its perceived utility for your agency.

	Very helpful	**Somewhat helpful, but still worth pursuing**	**Somewhat helpful, but not worth pursuing**	**Not very helpful**	**Unavailable to us**	**Unsure**
Driver registration data	○	○	○	○	○	○
Health information exchanges	○	○	○	○	○	○
Master Patient Index	○	○	○	○	○	○
LexisNexis	○	○	○	○	○	○
Other. (*Please specify in space provided.*)	○	○	○	○	○	○

Q12. Are there any comments you would like to provide on the utility of any of the above data sources?

Q13. How does your agency currently use the race/ethnicity data that you obtain? Select all that apply.

- ☐ Identifying disparities in disease incidence and burden (e.g., severity, hospitalization, mortality) across race and ethnic groups.
- ☐ Understanding access to mitigation measures such as vaccination or treatment across race and ethnic groups.
- ☐ Tailoring culturally appropriate messages for feedback and prevention for specific populations.
- ☐ Applying an equity lens to all activities within the PHA.
- ☐ Preparing stratified reports for governmental leadership and partners.
- ☐ Other. (*Please specify in space provided.*)

Q14. Not including the facilitators indicated earlier in the assessment, has your jurisdiction implemented any additional processes or measures that have improved the completeness and quality of race/ethnicity data for COVID-19? Please describe below.

Section 2: Sending Race/Ethnicity Data for COVID-19 from the Public Health Agency to the CDC

This set of questions focuses on understanding which factors affect your jurisdiction's ability to send obtained race/ethnicity data from your state or local public health agency (PHA) to the CDC.

Q15. Are there factors that affect your jurisdiction's ability to send obtained race/ethnicity data from your state or local PHA onward to the CDC?

- ☐ Yes, for case surveillance data.
- ☐ Yes, for laboratory report data.
- ☐ Yes, for vaccine administration data.
- ☐ Yes, for syndromic surveillance data.
- ☐ No, we send all collected race/ethnicity data onward to CDC.
- ☐ Unsure.

>>> IF respondent selects "No we send all collected race/ethnicity data onward to CDC." THEN SKIP to Q18.

All Else, PROCEED to Q16.

Q16. Please use the matrix below to indicate which factors affect your agency's ability to send race/ethnicity data for COVID-19 to CDC for each surveillance domain. Select all that apply.

	Case Surveillance Data	Laboratory Report Data	Vaccine Administration Data	Syndromic Surveillance Data
State law that limits or prohibits further sharing of race/ethnicity data.	☐	☐	☐	☐
Agency policy that limits or prohibits further sharing of race/ethnicity data.	☐	☐	☐	☐
Information system issues.	☐	☐	☐	☐
Race/ethnicity data can only be sent to CDC in aggregate.	☐	☐	☐	☐
Additional data processing is necessary in order to send race/ethnicity data to CDC.	☐	☐	☐	☐
Limited resources or staffing at the state public health agency.	☐	☐	☐	☐
Other factors.	☐	☐	☐	☐
Unsure	☐	☐	☐	☐

>>> IF none selected in matrix in Q16, THEN SKIP to Q18.

All Else, PROCEED to Q17.

Q17. [Will only carry forward responses selected in Q16] Is there additional information or detail that you would like to provide for any of the selected factors?

State law that limits or prohibits further sharing of race/ethnicity data.	
Agency policy that limits or prohibits further sharing of race/ethnicity data.	
Information system issues.	
Race/ethnicity data can only be sent to CDC in aggregate.	
Additional data processing is necessary in order to send race/ethnicity data to CDC.	
Limited resources or staffing at the state public health agency. collection.	
Other factors.	
Unsure.	

Q18. For each surveillance domain, what efforts or approaches would help facilitate your public health agency's ability to send more complete and accurate race/ethnicity data for COVID-19 onward to CDC?

- ○ Case surveillance data: _____
- ○ Electronic laboratory report data: _____
- ○ Vaccine administration data: _____
- ○ Syndromic surveillance data: _____

Q19. Are there any other comments not previously addressed that you would like to provide related to obtaining meaningful race/ethnicity data to inform public health action for COVID-19? Please describe below.

Thank you for your time and feedback in completing this assessment. Please contact Brooke Beaulieu (brooke@cste.org) at the CSTE National Office if you have any questions.

Please click the arrow forward to submit your responses.