Policy Recommendations:

Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data

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FEBRUARY 2021

BRIEF OVERVIEW

> As the COVID-19 pandemic swept across the country in 2020, it became clear that people of color, including African Americans, Latinx, Asian Americans, Native Hawaiians and Pacific Islanders, and American Indians and Alaska Natives, were disproportionately affected and more likely to be infected, hospitalized, and to die from COVID-19.

The COVID-19 pandemic continues to overwhelm our nation. Comprehensive data by racial and ethnic subgroups must be openly and transparently reported, collected, analyzed, and shared in order to fully understand and effectively address the pandemic, especially among the most vulnerable populations. While capturing this data is important to address COVID-19 now, it is also necessary in order to achieve long-term health equity. **The pandemic exposed the structural discrimination — and often, overt racism — inherent in our health care and public health systems.**

To address these inequities and discrimination, health care and public health systems need to change how they collect, analyze, and report data. The five broad categories in which data is currently and primarily collected — Black, White, American Indian/Alaska Native, Latinx, and Asian American/ Pacific Islander. These categories both ignore entire populations and thus perpetuate systemic injustices, and treat as monolithic the other demographic characteristics that can be more fully understood by further disaggregation such as by socio-economic level, age, and geography.

This policy brief provides a series of policy recommendations to address these inequities through legislation, regulatory changes, or policy guidance at both the state and federal level.

INTRODUCTION + SUMMARY OF THE PROBLEM

- State health data systems often do not adequately capture or enable reporting of information to accurately reflect the health status of all the diverse racial and ethnic populations in a state.

- Without a complete picture of health data for all state citizens, inequitable health and health care disparities and inequities can persist, and resources for impacted populations may not be appropriately identified or addressed.

- Reviewing subgroup data ("disaggregated data") allows state and other key stakeholders to better understand the health needs and inequities, better allocate resources, and develop more cost-effective and focused solutions for all communities within a state.

- Some state health agencies only capture and report health data by broad racial and ethnic categories (such as White, Black, or Hispanic/ Latino) and may include important subgroups in an "Other" category or combine them into a multiracial category. As a result, important data on disease prevalence, social risk, health care services and utilization, health insurance coverage, and causes of death for many racial and ethnic subgroups (such as American Indians/Alaska Natives, Asian Americans, Native Hawaiians and Pacific Islanders, Russians, Ethiopians, and Salvadorans) is not available.

- Some groups are often completely left out of data collection by state health agencies (Middle Eastern or North African, American Indian/ Alaska Native and Native Hawaiian and Pacific Islander).

- Data on a person's race, ethnicity, and language can inform the need for interpreter services, educational materials, and cultural competency training for staff who are providing services.

- Data on a population's race and ethnicity can inform the need for upstream efforts to impact the drivers of systemic inequities.

THE STATE DATA COLLABORATIVE REVIEW

Five national civil rights organizations conducted research on the current landscape of data disaggregation in all states to gain a better understanding of barriers, challenges, and opportunities for improving collection, analysis, and reporting of disaggregated data in order to address health disparities. The collaborative was funded by the Robert Wood Johnson Foundation. After a landscape analysis of all states, the collaborative focused on four priority states to develop strategy plans to advance data disaggregation towards improving health.

The policy recommendations for state data disaggregation included in this document were based on background research and conversations with state policymakers, state health agency staff, researchers, community advocates, and other interested key stakeholders.

The policy environment and political conditions in states will change and either facilitate or inhibit the ability of these recommendations to be considered, adopted, and/or implemented depending on each individual state conditions and current policies.

The following ***policy recommendations*** are a compilation of suggested legislative and regulatory changes along with suggested policy guidance and actions to take at the state level that will result in more data disaggregation to improve health. In addition to full disaggregation by the five main face and ethnicity categories described by the White House Office of Management and Budget (OMB), ***these recommendations were generated to encourage subgroup data disaggregation by more racial and ethnic categories.***

POLICY RECOMMENDATIONS

LEGISLATIVE CHANGES   REGULATORY CHANGES   POLICY GUIDANCE   POLICY ACTIONS

1. Enact legislation modeled after California AB 1726 (2016) that amends and expands 1) applicability for all departments in the Department of Public Health to ensure appropriate and uniform disaggregation of Asian and Pacific Islander subgroups among all primary producers of data and 2) disaggregation of additional racial and ethnic categories.

2. Modeled after California AB 1726, require state departments of public health to expand the number of Asian and Pacific Islander subgroups for which they collect and report data to also include Bangladeshi, Hmong, Indonesian, Malaysian, Pakistani, Sri Lankan, Taiwanese, Thai, Fijian, and Tongan Americans.

3. Require by legislation the standardization and utilization of the same race and ethnicity categories across all state public health data systems and enact adequate appropriations to allow for such standardization.

4. Enact legislation that requires health systems, including payers and providers, to collect, analyze, and report enhanced race and ethnicity data.

5. Enact legislation which mandates state agencies to develop, fund, and implement a structure to promote racial and ethnic health equity and to address racial and ethnic health disparities in the state.

6. Enact legislation to establish a Task Force on Racial and Ethnic Health Equity to serve as an advisory body within the state health department to study the causes of racial disparities in the COVID-19 pandemic and recommend actions to address such disparities, including Increasing transparency in reporting data regarding the racial and ethnic impact of COVID-19.

7. Enact legislation to require all health data reporting include the five OMB categories as a baseline, and then increase health reporting for racial subgroups.

8. Enact legislation that would provide funding for information system upgrades in order to fully implement enhanced data collection, analysis, and reporting among race and ethnic groups.

9. Enact legislation that ties data collection to healthcare outcomes. One way to create the impetus for change is to build in accountability. There are many silos that exist in the data world, from data collection, to analysis, to research, and reporting. Accountability would allow these artificial boundaries to be dismantled and data re-humanized for the benefit of improving health outcomes among racial and ethnically diverse communities.

10. Enact legislation that requires, in instances where privacy concerns are implicated, a statement disclosing why the data was not disaggregated further.

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1. Require by regulation the standardization and utilization of the same race and ethnicity categories across all state public health data systems.

3. Enact regulation that ties data collection to healthcare outcomes. One way to create the impetus for change is to build in accountability. There are many silos that exist in the data world, from data collection, to analysis, to research, and reporting.

2. Enact regulations that require health systems, including payers and providers, to collect, analyze, and report enhanced disaggregation of race and ethnicity data.

4. Regulation that requires, in instances where privacy concerns are implicated, a statement disclosing why the data was not disaggregated further.

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POLICY RECOMMENDATIONS

LEGISLATIVE CHANGES	REGULATORY CHANGES	**POLICY GUIDANCE**	POLICY ACTIONS

1. States should adopt Data De-Identification Guidelines (DDG), which require that all data be assessed prior to public release to determine whether any personal characteristics contained in the data pose the risk of identifying individuals.

2. The DDG should be transparently revisited for assessing increased risk of individual identification and the continued practice of limiting reporting by racial/ethnic categories in order to balance risk for publicly available reports.

3. Support innovations in data methods to balance between granularity and privacy/security matters. Different parts of the government can accomplish this, but they need adequate funding, not to be marginalized, and need an executive sponsor, such as in the Governor's office, to identify, replicate and scale such advancements in methodology.

4. Issue policy guidance that encourages, in instances where privacy concerns are implicated, a statement disclosing why the data was not disaggregated further.

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POLICY RECOMMENDATIONS

LEGISLATIVE CHANGES   **REGULATORY CHANGES**   **POLICY GUIDANCE**   **POLICY ACTIONS**

1. Release an Executive Order to establish a Task Force on Racial Disparities that will serve as an advisory body within the state health department to study the causes of racial disparities in the COVID-19 pandemic and recommend actions to address such disparities, including increasing transparency in reporting data regarding the racial and ethnic impact of COVID-19. Some states, including Michigan, have already done this.

2. Create a flowchart that follows race and ethnicity data from collection at the local site (e.g. hospital, testing site) to imputation into the state surveillance system and other collection systems, as well as any resulting analysis and reporting. Use the flowchart to inform how investments should be made to assure the collection, analysis and reporting of said data to enhance data disaggregation by race and ethnicity to improve health.

3. Advocate to update the state surveillance systems with additional race and ethnicity categories so that any change in data collecting standards could realistically be implemented. This would include advocating for the "Phase 2" data standards (see Appendix) which includes expanded options beyond the current OMB race and ethnicity categories.

4. Work directly with major producers of electronic medical record software to propose inclusion of disaggregated category options in their products.

5. At a minimum, review current state data collection, analysis, and reporting practices to ensure compliance with federal standards, such as collecting and reporting according to current Office of Management and Budget (OMB) standards, and other related agency reporting requirements, such as DHHS regulatory requirements.

6. Issue an Executive Order to require all health data reporting includes OMB categories as a baseline, and then improve health reporting for additional racial subgroups.

7. Update state data systems to reflect the current demographics of the state. Fully fund an analysis of current U.S. Census Bureau data on the state racial and ethnic composition of the population in the state to inform the need for inclusion of any additional or new racial and ethnic categories in state data collection systems including disease surveillance systems, vital statistics, and state health surveys. If state legislation is necessary, enact statutory language requiring updates to racial and ethnic categories for state agency data collection systems within a reasonable amount of time.

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POLICY RECOMMENDATIONS

LEGISLATIVE CHANGES   **REGULATORY CHANGES**   **POLICY GUIDANCE**   **POLICY ACTIONS**

8. Standardize racial and ethnic categories in data collection tools across all state health agencies. Various health agencies within a state may collect race and ethnicity data using different categories or terms. This prevents accurate sharing of data across platforms that could be valuable in better understanding the underlying factors and drivers that impact the health of different communities. Standardization across agencies may also require state legislative action.

9. Implement Privacy Protections for Releasing Disaggregated Data. Even if state health data systems have been updated to reflect categories representative of the state's population, implement methods such as pooling of data over time and analysis for larger areas and regions to protect privacy and allow the release of data for small sample sizes in a protected manner.

10. Partner with Health Systems. State health agencies should explore partnership opportunities with health systems, payers, providers, and Electronic Medical Record suppliers to add racial and ethnic subgroups to their data collection tools.

11. Support enhanced staff and resources for state data collection, analysis, and reporting to ensure that if a greater range of racial and ethnic categories is adopted, resources and staff are available to analyze and report this data in a timely manner to the public.

12. Adopt a consistent standard for collecting, analyzing, and reporting data by race and ethnicity across states to enable better comparisons of health disparities and encourage more collaboration among states with similar diversity in populations served.

13. Enact an Executive Order that requires each state agency, in instances where privacy concerns are implicated, provide a written statement disclosing why the data was not disaggregated further.

14. Convene diverse stakeholders and coalitions in each state to discuss priorities for further data disaggregation.

15. Consult with tribal nations on the best ways to collect and report state-level tribal data for American Indians and Alaska Natives; some tribal nations may not want tribal level data reported publicly but will want it used in local policy decisions. Data sharing agreements are needed to govern the ownership, use, and protection of tribal data.

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APPENDIX: Model/Sample Recommended Standard for Health Data Collection, Analysis, & Reporting by Race/Ethnicity

The State Data Collaborative reviewed various examples of standards for the collection, analysis, and reporting of health data by race and ethnicity and **recommends the following standard** for use by states as they review the diversity of their population and work to improve disaggregation of health data to inform policy.

WHAT IS THE PERSON'S RACE OR ORIGIN?

Mark all boxes that apply and print origins in the spaces below.
Note, you may report more than one group.

○ **White:**
Print, for example, German, Irish, English, Italian, Polish, French, etc.
_____

○ **Hispanic, Latino, or Spanish origin:**
Print, for example, Mexican or Mexican American, Puerto Rican, Cuban, Salvadoran, Dominican, Colombian, etc.
_____

○ **Black or African American:**
Print, for example, African American, Jamaican, Haitian, Nigerian, Ethiopian, Somali, etc.
_____

○ **Don't Know**
_____

○ **Unsure**
_____

○ **Decline to State**
_____

○ **Middle Eastern or North African:**
Print, for example, Lebanese, Iranian, Egyptian, Syrian, Moroccan, Algerian, etc.
_____

○ **Native Hawaiian or Pacific Islander:**
Print, for example, Native Hawaiian, Samoan, Chamorro, Tongan, Fijian, Marshallese, etc.
_____

○ **Asian:**
Print, for example, Chinese, Filipino, Asian Indian, Vietnamese, Korean, Japanese, etc.
_____

○ **American Indian or Alaska Native:**
Print your tribal affiliation, for example, Navajo Nation, Blackfeet Tribe, Mayan, Aztec, Native Village of Barrow Inupiat Traditional Government, Nome Eskimo Community, etc.
_____

○ **Some other Race or Origin:**
_____

APPENDIX: *Model/Sample Recommended Standard for Health Data Collection, Analysis, & Reporting by Race/Ethnicity*

Additional recommendations for state health data collection and reporting on race and ethnicity using these recommended standards:

- Review race and ethnicity health data categories at least once every five years and update if necessary to align with current state population numbers from the U.S. Census Bureau Decennial Census or American Community Survey.

- Consult with tribal nations on the best ways to collect and report state-level tribal data for American Indians and Alaska Natives; some tribal nations may not want tribal level data reported publicly but will want it used in local policy decisions. Data sharing agreements are needed to govern the ownership, use, and protection of tribal data.

- When race and ethnicity data is not reported by state health departments using the minimum categories, any publication should include a brief explanation for why the data was not reported.

- Allow respondents to select one or more categories.

- If not feasible to include a write-in option, create individual checkbox options for all subcategories. Checkboxes for subcategories should be reflective of race and ethnicity based on current Census Bureau data.

- Develop a rubric for how to capture and report multiracial data and publish when reporting data.

- Avoid combining data on distinct groups (such as combining American Indian/Alaska Native with Native Hawaiian Pacific Islander data).