



HIDDEN IN PLAIN SIGHT

Revealing Health Disparities Through Equitable
Data Collection During the Covid-19 Pandemic

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LAWYERS' COMMITTEE FOR
CIVIL RIGHTS
UNDER LAW

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LETTER FROM THE PRESIDENT & EXECUTIVE DIRECTOR


The COVID-19 pandemic has claimed approximately one million lives in the United States. This staggering figure includes over 200,000 Black and Latinx lives, as well as the lives of more than 30,000 Asian, Native, and Indigenous people. Our communities have lost parents, children, siblings, grandparents, aunts, and uncles. Our teachers, friends, colleagues, and mentors have also fallen to this deadly virus. Though the COVID-19 pandemic is unprecedented, the racial and economic health disparities the pandemic laid bare are not. Black, Indigenous, and other communities of color have long endured worse health and economic outcomes relative to their white counterparts. The pandemic has threatened to further entrench these disparities as part of the fabric of American society for generations to come.

Although most know, anecdotally, that health outcomes have been worse for people of color, a lack of complete demographic data obscures the pandemic's true impact on our communities. Moreover, public health and health care experts have long recognized that disaggregated race and ethnicity data—data that captures diverse subgroups within major race and ethnic categories of people—is a critical component to addressing racial health disparities. However, there have been no serious efforts at either the federal or state level to collect health data beyond five major racial groups (American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian or Other Pacific Islander, and White) and two ethnic groups (Hispanic and non-Hispanic). Nor has there been a

widescale, national effort to collect demographic health data beyond race and ethnicity, although various social determinants of health impact diverse groups in unique ways.

Facing a dearth of demographic data at the beginning of the pandemic, the Lawyers' Committee developed a nationwide advocacy campaign calling upon states, as well as the Centers for Disease Control ("CDC"), to collect and publish race and ethnicity data on COVID-19 cases and death rates. Soon after, both states and the federal government began publishing some demographic data detailing the pandemic's impact. The Lawyers' Committee then reviewed demographic data published by each state and the CDC. Although the available data revealed Black, Latinx, and American Indian Alaskan Native ("AIAN") people were becoming infected and dying at significantly greater rates than white people, the information was woefully incomplete and varied widely across the states.

The problems with the available state and federal data were multi-fold. First, many states did not publish data according to federal standardized categories and most states failed to publish disaggregated data for each racial and ethnic group. As a result, the pandemic's impact on diverse subsets of people went entirely unreported. Second, no two states reported the same race or ethnicity data. This has made comparison and analysis challenging for health professionals and the general public alike. Moreover, only a handful of states went beyond race and ethnicity to also



publish socio-economic data, such as income, housing, and employment type, although each of these metrics represent a social determinant of health. Sexual orientation and gender identity were also ignored in state data collection efforts. These data gaps and inconsistencies have deprived impacted communities from understanding the full picture of the pandemic's immense toll. Data gaps have also undoubtedly hamstrung health and safety intervention efforts at every stage, leading to unnecessary death, illness, and a host of other consequences not just for communities of color, but across the demographic spectrum.

During a global pandemic, complete demographic data can serve as a canary in a coal mine. This report therefore calls for the collection of “equitable data”—that is, data that reveals health outcomes at the intersections of multiple identities and socio-economic factors. Without this data, barriers to quality health care, as well as discriminatory systems and practices in health care, may continue unabated. This report and its detailed recommendations should serve as a tool for policy experts, health care system employees, public health experts, and community advocates to expand health care data. This, we argue, is critical to rectifying disparities illuminated by the COVID-19 pandemic and beyond.

Damon T. Hewitt

President and Executive Director
Lawyers' Committee for Civil
Rights Under Law

EXECUTIVE SUMMARY

In 1985, the federal government issued a report that recognized—for the first time—the “continuing disparity in the burden of death and illness experienced by Black people and other minority Americans as compared with our nation’s population as a whole.”¹ That report, issued by the United States Department of Health and Human Services (“HHS”) Task Force on Black and Minority Health (“Minority Health Task Force”), acknowledged the critical role that reliable racial and ethnic demographic data plays in addressing health disparities:


Reliable data are central to measuring progress in public health, and are the key to assessing the current health status of the Nation and measuring health status trends; recognizing both sources of and solutions to problems; identifying health disparities between segments of the population; and targeting efforts directly to specific needs.²

Yet, almost 40 years later, there remains a dearth of health care data reflecting diverse populations and people living at the intersections of multiple identities. Worse, our health care system remains replete with stark disparities, as people of color and other systemically marginalized populations continue to die at about twice the rate of white people from COVID-19.³ These disparities reflect the severity of racial health inequities that plague communities of color. For example, Black and American Indian and Alaskan Native (AIAN) people have the highest cancer mortality and shortest survival time of any racial or ethnic group, despite overall reduction in death among all groups.⁴ Likewise, according to a 2020 report by the Centers



for Disease Control and Prevention (“CDC”), the prevalence of diagnosed diabetes was highest among AIAN (14.7%), people of Hispanic origin (12.5%), and non-Hispanic Black people (11.7%).⁵ Similarly, Black people have the highest prevalence of Alzheimer’s disease and related dementias (13.8%), followed by Hispanics (12.2%), among people 65 and older.⁶ It bears noting that each of these diseases and illnesses are correlated with greater risk of severe illness from COVID-19 infection. Thus, as the adage goes: “When White people catch a cold, Black people catch pneumonia.”⁷

Our health care system remains replete with stark disparities, as people of color and other systemically marginalized populations continue to die at about twice the rate of white people from COVID-19.



Better national standards and uniform COVID-19 data collection practices at the state level could have an outsized impact on efforts to narrow health disparities, as well as other illness and disease given the pandemic's broad intersections with a variety of health conditions. Ultimately, data should aim to reveal health disparities between groups and encourage health care systems, providers, and public health professionals to correct the inequitable delivery of health care resources based upon community need. The need may vary based upon differing cultural attitudes and values and broad socio-economic factors, such as income, job type, housing status, or access to transportation. Failure to deliver health care resources, such as COVID-19 vaccines and testing, without taking these factors into consideration merely allows existing inequities to persist and, in many cases, worsen.

Data should aim to reveal health disparities between groups and encourage health care systems, providers, and public health professionals to correct the inequitable delivery of health care resources based upon community need.

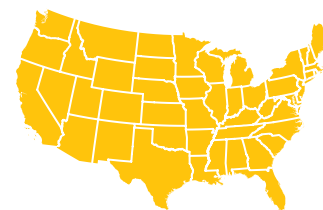
However, during the greatest public health crisis in a century, efforts to collect even minimal demographic data relating to the pandemic have been inadequate. More than two years into the pandemic, the CDC was still missing federal race and ethnicity data for 37% of all COVID-19 cases as of April 30, 2022, although there was age and sex data for nearly all cases.⁸ Likewise, the CDC lacks race and ethnicity data for approximately 25% of people who have received at least one dose of the COVID-19 vaccine.⁹ This data gap endures despite legislation mandating the collection of COVID-19 race and ethnicity data, administrative support from the CDC for data collection efforts,¹⁰ as well as an Executive Order, titled *Ensuring an Equitable Pandemic Response*

and Recovery, issued by President Biden.¹¹ That Executive Order stressed that “[t]he lack of complete data, disaggregated by race and ethnicity, on COVID-19 infection, hospitalization, and mortality rates, as well as underlying health and social vulnerabilities, has further hampered efforts to ensure an equitable pandemic response.”¹² Yet, 16 months later, the data gap regarding race and ethnicity for vaccinations and cases remained nearly stagnant.

Missing COVID-19 case data at the federal level is largely attributable to insufficient data collection by health care providers, testing and vaccine distributors, and laboratories. These entities share data collected with state, tribal, and local public health jurisdictions, which, in turn, share data with the CDC.¹³ Data collected at the state level is thus a significant primary source for the data published by the federal government. However, the data collected from one state to the next is often incongruent and misaligned. A 50-state survey conducted by the Lawyers’ Committee in 2021 analyzed the types of data published by states and found that no two states publish the same COVID-19 demographic data.¹⁴

Moreover, the survey showed that the failure to disaggregate health data by race and ethnicity plagues states just as much as the federal government. In fact, both state and federal data collection systems, which are intertwined, have entirely neglected to publish disaggregated racial and ethnic data for COVID-19 testing rates, hospitalizations, and ICU admissions.¹⁵ Our survey also revealed that, during the first year of the pandemic, only a small number of states published demographic or socio-economic data beyond race and ethnicity, such as employment type/income, disability status, gender identity/sexual orientation, housing status, pregnancy status, and insurance status.^{16,17} Unsurprisingly, efforts to address health disparities during the pandemic have been severely limited. Black and Latinx people, for example, received booster shots at significantly lower percentages (40.4% and 43.5%) than White and Asian people (54.3% and 60.1%) as of April 2022.¹⁸

A 50-state survey conducted by the Lawyers' Committee in 2021 analyzed the types of data published by states and found that no two states publish the same COVID-19 demographic data.



Moreover, current federal and state demographic data standards simply do not reflect the needs that have been acknowledged by the federal government for almost 40 years. The standards the federal government uses for COVID-19 data collection—the Office of Management and Budget’s 1997 standards (“1997 OMB Standards”)—are nearly 25 years old.¹⁹ These standards require the inclusion of only five racial (Black or African American, Asian, White, American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander) and two ethnic (Hispanic or Latino, Not Hispanic or Latino) categories in federal data collection efforts.²⁰ Many states simply follow the federal government’s lead, and others neglect to collect data on each group reflected in the 1997 OMB Standards.

But, better racial and ethnic demographic data standards do exist. HHS promulgated more exacting standards in 2011 (“2011 HHS Data Standards”) under Section 4302 of the Affordable Care Act (“Sec. 4302”).²¹ The 2011 HHS Data Standards disaggregate the “Asian,”

“Native Hawaiian or Other Pacific Islander,” and “Hispanic or Latino” categories into subgroups, thus providing more detailed information about the distinctive health outcomes of subgroups within these massive populations.²² So far, and for no legal reason, the 2011 HHS Data Standards have been applied only to national population health surveys.²³ Moreover, HHS and the CDC have failed to require that their own COVID-19 data tools capture this critical information. Three of the federal government’s main COVID-19 data collection channels—the CDC’s Case Report Form/Surveillance Worksheet, the CDC’s COVID-19 Vaccination Program, and V-safe, a smartphone app for recording adverse vaccine events—ask only for race/ethnicity demographic data using the outdated 1997 OMB Standards.²⁴ These channels also largely ignore two other categories of demographic data required under Sec. 4302—primary language and disability status.²⁵ Neither the CDC nor the majority of state public health jurisdictions and health care systems endeavor to collect broad socio-economic data, either.

Recommendations

To address these challenges, federal, state, and local public health authorities must enhance their data collection strategies to ensure responses to the current health crisis address persistent health inequities. This report therefore makes the following 14 recommendations for key actors and policymakers at various levels of industry and federal, state, and local government:



Congress should:

- Authorize funds to provide testing, vaccination, and treatment for uninsured people. Without funding, people most likely to be infected will be the least likely to obtain care. Consequently, there will be a dearth of data pertaining to these populations.



At the federal level, HHS should issue guidance:

- Clarifying that all COVID-19 data collection tools should collect race, ethnicity, primary language, and disability information per the 2011 HHS Data Standards for public health surveys, pursuant to its authority under Sec. 4302 of the Affordable Care Act.
- Directing labs, health care providers, and hospitals to collect COVID-19 health care and health outcome data, disaggregated by race and ethnicity, in each of the following categories: (1) COVID-19 tests administered; (2) hospitalization rates; (3) ICU admissions; (4) comorbidities; (5) disability status/type; (6) insurance status; and (7) pregnancy status.
- Directing health care entities, including laboratories, hospitals, health care providers, and vaccine providers, to collect, report, and publish demographic COVID-19 data in each of the following categories: (1) sexual orientation and gender identity; (2) employment type and income; and (3) housing status.



HHS and the CDC should:

- Provide training to health care providers on equitable data collection practices, in conjunction with state and local public health departments. The outcomes of this training should be to increase the rates at which providers collect demographic data and the quality of that data, as well as to develop strategies for overcoming hesitations communities may have in providing demographic information.
- Develop and distribute standardized COVID-19 case forms that include sufficient space for demographic data collection. These forms should collect, at minimum, the 14 race and five ethnicity categories specified by the 2011 HHS Data Standards, pursuant to HHS's authority under Sec. 4302 standards. The forms should also provide space for collecting the remaining demographic categories specified above, to the extent those categories are not already included.
- Ensure that all COVID-19 data collected directly by the federal level through programs such as V-safe and FEMA-run vaccination sites, is disaggregated according to the 2011 HHS Data Standards, pursuant to its express authority under Sec. 4302 of the Affordable Care Act.
- Provide funding and technical assistance to ensure health information technology systems upgrades can happen as quickly as possible.



At the state/local/territorial level, public health authorities should:

- Require health care entities within their jurisdiction to collect COVID-19 health care and health outcome data disaggregated by race and ethnicity in each of the following categories: (1) COVID-19 tests administered; (2) hospitalization rates; and (3) ICU admissions.
- Provide raw COVID-19 data that would allow non-state-affiliated organizations to create their own databases and presentations of data that may better reach their relevant communities.
- Engage in direct one-on-one educational efforts with laboratories and providers regarding the collection of demographic data, especially for entities that fail to regularly report this data.
- Conduct public education campaigns regarding the importance of providing demographic information, including culturally and linguistically appropriate information provided to people to whom tests are administered.



Public health authorities, health care providers, hospitals, vaccine providers and laboratories must:

- Upgrade outdated health information technology systems throughout the entire data supply chain. All systems should collect detailed demographic data that are in line with the standards developed by the Office of the National Coordinator for Health IT and must be interoperable.
- Collect COVID-19 data on: (1) sexual orientation and gender identity; (2) comorbidities; (3) employment type and income; (4) pregnancy status; (5) housing status; (6) hospitalization rates; (7) ICU admissions; (8) disability status/type; and (9) insurance status.

At no point in recent history has the need for detailed and disaggregated data been more apparent. The COVID-19 pandemic presents an opportunity for the federal government and states to ensure the equitable collection of data that is uniform, comprehensive, and useful in the effort to minimize health disparities during the COVID-19 pandemic and beyond. They must rise to meet this once-in-a-generation occasion.

DEFINITIONS AND METHODOLOGY

The phrase “equitable data,” as used in this report, recognizes that race, ethnicity, identity, language, physical status, and a number of social determinants of health²⁶ combine to drive incidence, identification, treatment, and outcomes of disease and illness. Though not the sole remedy to racial health disparities, equitable data is the foundation to better understanding and addressing poor health outcomes, especially for people living at the intersections of multiple identities. Indeed, “vulnerable communities aren’t all vulnerable in the same way.”²⁷ As such, data that promotes equity in health care must encompass race and ethnicity disaggregated into subgroups, rather than consolidated into broad categories that do not distinguish between diverse populations who experience unique and varying social determinants of health.

Equitable data also requires the collection of primary language, disability status, housing status, pregnancy status, employment status and type, insurance status, sexual orientation, and gender identity metrics. Equitable data must also track the distribution and utilization of various health care resources. Such resources include screening, testing, and treatment for a variety of illnesses and diseases that disproportionately afflict communities of color and other systemically marginalized populations, yet are often inaccessible to these very groups. Health care data that do not track these vital demographic metrics are incomplete and restrict efforts to deliver health care resources that address the full impact of disease incident, including COVID-19, on those living at the intersection of multiple marginalized identities.

Equitable data must also track the distribution and utilization of various health care resources.

Just weeks into the COVID-19 pandemic, the Lawyers’ Committee for Civil Rights Under Law, with the support of over 400 medical professionals, issued a letter to HHS and the CDC urging the federal government to release detailed race and ethnic demographic data related to COVID-19 diagnoses, tests, and outcomes.²⁸ Though slow to respond, the agencies eventually published the minimal data they had collected.²⁹ Our review of this public data revealed a disturbing truth: HHS and the CDC were, and still are, failing to capture race/ethnic demographic data for a substantial portion of people seeking treatment for COVID-19.³⁰ In an effort to understand the reason for these colossal gaps, we analyzed the standards and regulations that currently govern COVID-19 data collection. We found that current data collection tools use outdated demographic standards that have long been recognized as inadequate for addressing health disparities amongst communities of color and other systemically marginalized groups.³¹

The Lawyers’ Committee and our pro-bono partners also surveyed each state’s COVID-19 website to evaluate the different data collection standards and processes employed across the country.³² Throughout much of the first year of the pandemic, most states published demographic data, and New York was the only state that did not publish any race/ethnicity demographic data related to COVID-19 cases.³³ All states except New

Mexico and North Dakota reported some race/ethnicity demographic data related to COVID-19 deaths.³⁴ And 47 states collected and reported some race and ethnicity demographic data for vaccinations.³⁵ However, no two states published the exact same race and ethnicity demographic data.

Moreover, state race/ethnicity demographic data is often missing entirely for important metrics, like COVID-19 testing and hospitalization rates. Only nine states and Washington, D.C. published race and ethnicity data for COVID-19 tests³⁶, and less than half of states published hospitalization data disaggregated

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by race and ethnicity.³⁷ This is hardly surprising, as the federal government also does not report racially disaggregated hospitalization and testing information.



INTRODUCTION

In 1984, Margaret M. Heckler,³⁸ then-Secretary of the U.S. Department of Health and Human Services (“HHS”), established the Task Force on Black and Minority Health (“Minority Health Task Force” or “Task Force”) to address “a continuing disparity in the burden of death and illness experienced by Blacks and other minority Americans.”³⁹ The Task Force’s “broad assignment was the comprehensive investigation of the health problems of Blacks, Native Americans, Hispanics, and Asian/Pacific Islanders.”⁴⁰ One year later, at the conclusion of their investigation, the Minority Health Task Force released a report titled Report of the Secretary’s Task Force on Black and Minority Health (“1985 Report” or “Report”).⁴¹ The Report identified six chronic illnesses that served as drivers of health disparities across communities of color⁴² and

six categories of recommendations to: (1) help to reduce the health disparities affecting communities of color; and (2) help communities of color fully benefit from advances in science, medicine, and health care.⁴³ In their recommendations, the Task Force emphasized the fundamental need to “[i]mprove data collection and interpretation of data regarding specific minority groups,”⁴⁴ stating:

Reliable data are central to measuring progress in public health, and are the key to assessing the current health status of the Nation and measuring health status trends; recognizing both sources of and solutions to problems; identifying health disparities between segments of the population; and targeting efforts directly to specific needs.⁴⁵



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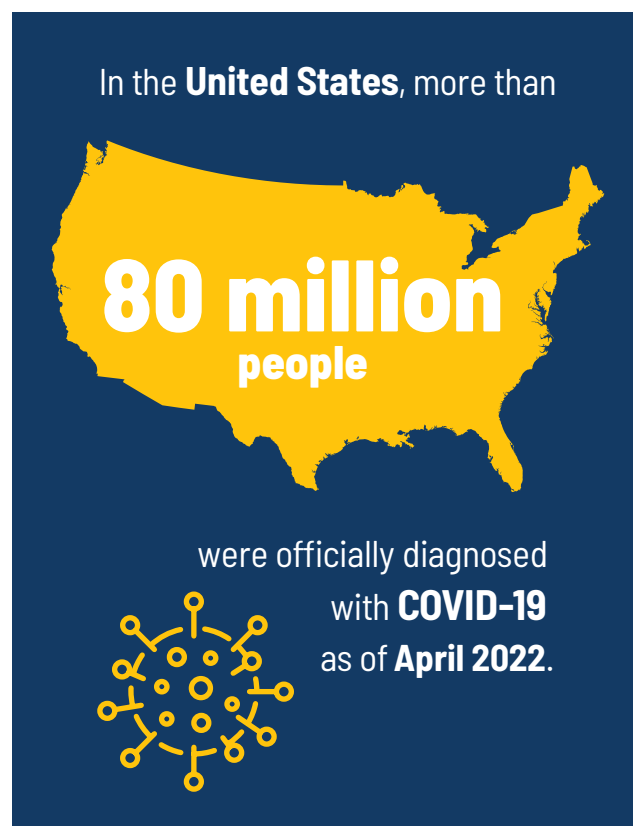
Thus, as long ago as 1985, the federal government explicitly acknowledged that detailed race/ethnicity demographic data is critical to “program planning, implementing, and monitoring” racial health disparities and health outcomes.⁴⁶ Indeed, equitable health data is necessary to identify and dismantle barriers to health care resources that drive health disparities.

In many instances, relying upon incomplete data can worsen health inequities. In the United States, more than 80 million people were officially diagnosed with COVID-19 as of April 2022.⁴⁷ The available COVID-19 data continue to reveal stark disparities along racial and ethnic lines. Communities of color continue to get sicker and die at higher rates than their white counterparts.⁴⁸ For example, recent data indicates AIAN, Black, and Latino people are 3.1, 2.4, and 2.3 times as likely to be hospitalized from COVID-19 infection than white people, respectively.⁴⁹ These same groups were approximately twice as likely to die from COVID-19 as white people.⁵⁰ And, despite the disproportionate impact the pandemic has had on these communities, people of color and other systemically marginalized groups still face significant barriers to accessing the vaccine.⁵¹

Yet, there is still a dearth of reliable race and ethnicity demographic data related to the virus—a problem intrinsic to public health more broadly. According to the Kaiser Family Foundation, race and ethnicity data is missing for substantial portions of COVID-19

cases in several states. For example, race and ethnicity data was missing for 100% of COVID-19 cases in North Dakota, 81% of cases in Louisiana, and 65% of cases in Connecticut nearly two years into the pandemic.⁵² Similarly, the Kaiser Family Foundation reported that many states fail to report race and ethnicity data for vaccinations. For example, months after the vaccine rollout, less than 1% of vaccinations administered in South Dakota included race and ethnicity data, and 19 states reported this information for less than 10% of vaccines administered.⁵³ The CDC reports that, nationally, race and ethnicity is missing for about one-third of people who have received at least one dose of the COVID-19 vaccine.⁵⁴ Astonishingly, there is no federal race and ethnicity data on vaccinated individuals who become infected with COVID-19, unless the infection results in hospitalization or death.⁵⁵

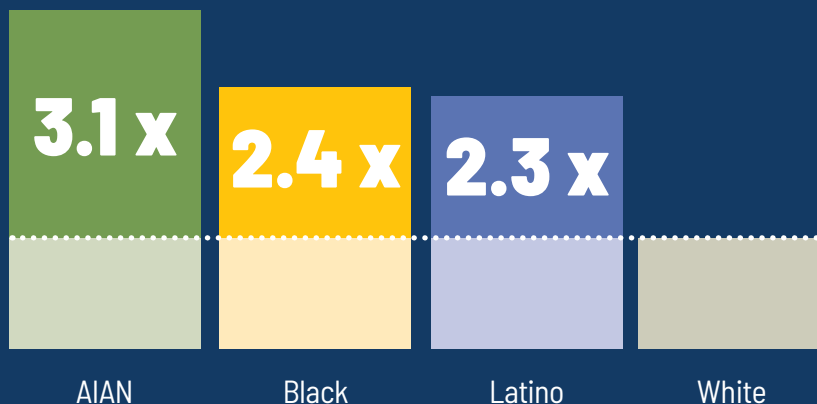
This report addresses the collection of equitable data—data that encompasses race, ethnicity, identity, physical status, and a number of social determinants



of health—in three parts. Part I discusses the need for disaggregated race and ethnicity data amid a decades-long effort to collect such information. Part II highlights the need for demographic data beyond race and ethnicity. Part III provides policy and practical recommendations to aide in the collection of

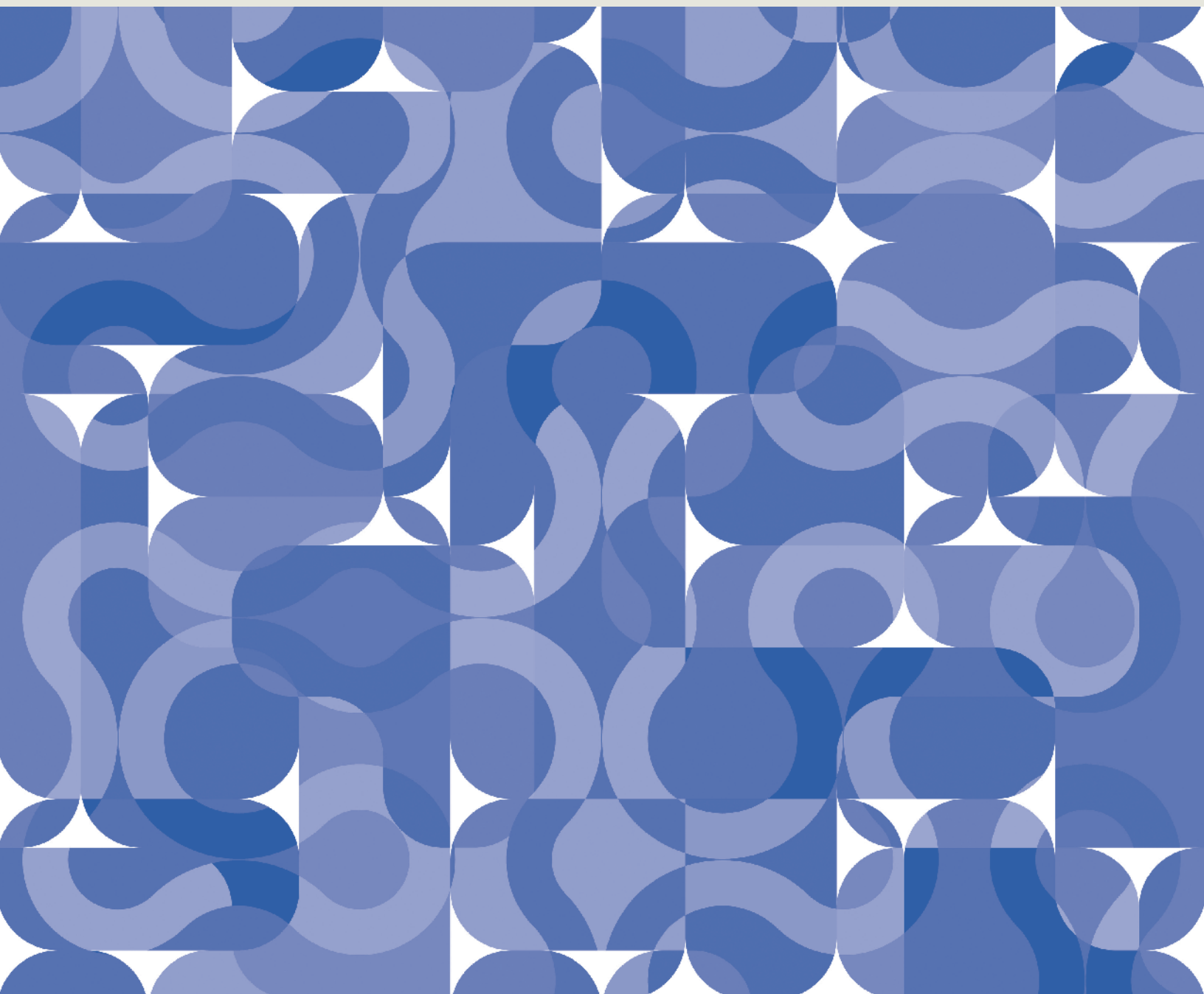
demographic data that can help correct disparities that produce poor health outcomes in systemically marginalized populations. This report, ultimately, highlights the fundamental fact, true in 1985 and still true today, that “[r]eliable data are central to measuring progress in public health.”⁵⁶

People of Color
are more likely than
white people to be
hospitalized with
COVID-19



PART I

DISSAGGREGATED RACE AND ETHNICITY DATA: 40 YEARS OF MISSED OPPORTUNITIES




Disaggregated race and ethnicity data is the cornerstone of any equitable data collection effort but is thus far lacking at both the federal and state level. There are vast disparities in health outcomes for people from different geographical ancestry and cultural backgrounds, despite sharing common regional points of origin. To highlight this point, and the need for greater disaggregation of racial health data, the 1985 Minority Health Task Force commissioned thorough death analyses for Chinese, Japanese, and Filipino subgroups.⁵⁷ The report stressed “the lack of data for other Asian/Pacific Islander subgroups, such as Southeast Asians and Native Hawaiians,” while pointing out that their “health status is believed to be poorer than that of those Asians for whom data are available.”⁵⁸ The 1985 Report similarly opined that “[t]he relative paucity of data on Puerto Ricans, Cubans, and other Hispanics precludes any conclusions about whether health behaviors could account for any differences

in cardiovascular disease risk between these groups and non-Hispanic Whites.⁵⁹ Yet, the collection of disaggregated race and ethnicity data has proven to be a significant challenge in the effort to address racial health disparities.

Today, race and ethnicity data continues to mask pertinent health data for communities of color. For example, in the aggregate “Asians,” who represent 40 countries and vastly different socio-economic realities, are reported as having roughly comparable uninsured rates with white people, at 7.3% and 6.3% respectively.⁶⁰ When disaggregated, however, Burmese Americans have uninsured rates over twice as high (13.2%)⁶¹ as

Today, race and ethnicity data continues to mask pertinent health data for communities of color.





their white counterparts (6.3%).⁶² Similarly, Latinx groups should not be treated as a monolith in terms of health disparities. Puerto Rican people, for instance, have a much higher prevalence of asthma (16%) compared to non-Latinx Whites (7.7%).⁶³ In contrast, those of Mexican origin have a lower prevalence of asthma (5.4%) compared to non-Latinx Whites.⁶⁴

Similarly, African immigrants have lower rates of risk factors for heart attacks, strokes, and other cardiovascular diseases compared to Black Americans.⁶⁵ Moreover, according to one study, high blood pressure was 17% for African immigrants; 32% for Afro-Caribbean; and 42% for African Americans.⁶⁶ And, only 76% of African immigrants had health insurance, compared to 81%, 83%, and 91% of Afro-Caribbeans, African Americans and white Americans, respectively.⁶⁷

In truth, any number of social determinants of health between ethnic groups can combine to direct health outcomes. Social factors, such as living environment, education level, and access to health services may all contribute to health outcome.⁶⁸ Disaggregated race and ethnicity data with “specific minority identifiers,” as called for in the 1985 Report, is not just useful, but necessary to mitigate the spread and severity of illness, including the COVID-19 virus, in communities of color.^{69,70}

The 1985 Report specifically warned against the “over-aggregation” of race/ethnicity data and noted that improvements in data development were “urgently needed.”⁷¹ Yet, the federal government has been slow to modify existing racial and ethnic demographic categories in the decades since, leaving it wholly unprepared to tackle data collection during a health crisis like COVID-19. As discussed below, the federal government has failed to expand data collection efforts at various points over the past several decades.

For example, the Office of Management and Budget (“OMB”) did not require sufficiently disaggregated race and ethnicity data when it updated the data collection standards for all federal agencies in 1997. Then,

The federal government has failed to expand data collection efforts at various points over the past several decades

following the passage of the Affordable Care Act, the HHS did not expand disaggregated data collection efforts to all federal health-related activities. Today, federal COVID-19 data collection guidance requires only that laboratories, hospitals, and vaccine providers collect inadequate race and ethnicity demographic data information.⁷² This inaction has meant that the federal government has missed a crucial opportunity to revamp the inadequate health data standards and directives that have persisted for far too long.

A. Office of Management and Budget Data Collection Standards

In 1977, OMB established standards for the collection and reporting of race and ethnic demographic data for *all* federal agencies.^{73,74} At that time, OMB required federal agencies to track only four racial groups: (1) American Indian or Alaskan Native, (2) Asian or Pacific Islander, (3) Black, (4) White; and two ethnic groups: “Hispanic origin” or “Not of Hispanic origin.”⁷⁵ The Minority Health Task Force’s subsequent 1985 Report found that these standards were “too broad to permit delineation between subgroups” and that “diversity within and among minorities necessitates activities, programs, and data collection tailored to meet their health needs.”⁷⁶ The Task Force recommended that “all DHHS agencies that collect health data from individuals to include race and ethnic identifiers, as defined by OMB” and “[w]here possible and desirable, further breakdown within racial and ethnic categories should be recorded, e.g., national origin of Hispanics and Asian/Pacific Islanders.”⁷⁷

In 1997, OMB made minor adjustments to their race and ethnicity demographic data collection standards. Over a decade after the Minority Health Task Force’s report was released, OMB included “Hawaiian

Current OMB Minimum Categories

RACE

American Indian or Alaska Native
Asian
Black or African American
Native Hawaiian or Other Pacific Islander
White



ETHNICITY

Hispanic or Latino
Not Hispanic or Latino

or Other Pacific Islander” as a separate sub-category from “Asian,” allowed respondents to select multiple racial identities, and added “African American” to the “Black” subgroup.⁷⁸ OMB considered creating an “Arab/Middle Eastern” category, but failed to do so due to definitional disagreement.⁷⁹ Notably, the 1997 OMB Standards also did not disaggregate various Latinx ethnic subgroups within the existing “Hispanic or Latino” category, though the Minority Health Task Force’s Report underscored that the “relative paucity of data on Puerto Ricans, Cubans, and other Hispanics” limits public health efforts directed toward these groups.⁸⁰ Unfortunately, these broad racial and ethnic categories have not been meaningfully updated in the past 24 years, except in the limited circumstances noted below.

B. Section 4302 of the Affordable Care Act

The Affordable Care Act (“ACA”) served as another opportunity for HHS to finally implement comprehensive data collection standards in health care and public health activities. Section 4302 of the ACA (“Sec. 4302”) requires that “any federally conducted or supported health care or public health program, activity or survey ... collects and reports, to the extent practicable, data on race, ethnicity, sex, primary language, and disability status for applicants, recipients, or participants.”⁸¹ As to race, Sec. 4302 directs the HHS Secretary to “use [OMB] standards, *at a minimum*, for race and ethnicity measures.”⁸² It instructs HHS to disaggregate race/ethnicity data into the five racial subgroups and two ethnic subgroups detailed in the 1997 OMB

Standards as a starting point, but gives the agency broad latitude to collect more detailed race/ethnicity demographic data.⁸³

In response to the ACA’s directives, HHS promulgated new race and ethnicity demographic data collection standards beyond the minimum 1997 OMB requirements.⁸⁴ The new guidance was implemented in 2011 and titled the HHS “Implementation Guidance On Data Collection Standards For Race, Ethnicity, Sex, Primary Language and Disability Status” (“2011 HHS Data Standards” or “2011 Standards”).⁸⁵ The 2011 HHS Data Standards established enhanced disaggregated standards for the collection of race/ethnicity demographic data, now tracking 14 different race subgroups and five different ethnic subgroups.⁸⁶ Under the 2011 HHS Data Standards, “Asian Indian,” “Chinese,” “Filipino,” “Japanese,” “Korean,” “Vietnamese,” and “Other Asian” are disaggregated within the “Asian” subgroup.⁸⁷ “Native Hawaiian,” “Guamanian or Chamorro,” “Samoan,” and “Other Pacific Islander” are disaggregated within “Native



The ACA does not prevent HHS from adopting the more detailed 2011 Standards for all public health programs and activities, like COVID-19 surveillance.

Hawaiian or Other Pacific Islander.”⁸⁸ As to ethnicity, the 2011 Standards disaggregates “Puerto Rican,” “Cuban,” and “Mexican, Mexican American, or Chicano/a” from the “Hispanic or Latino” ethnic subgroup.⁸⁹

These additional racial/ethnic demographic subgroups represent a marked expansion of the 1997 OMB standards.⁹⁰ However, the 2011 HHS Data Standards are only used for “national population health surveys.”⁹¹ This is a self-imposed limitation; the ACA does not prevent HHS from adopting the more detailed 2011 Standards for all public health programs and activities, like COVID-19 surveillance.^{92,93} And, by failing to include these enhanced racial and ethnic categories in other health data collection activities, HHS has shirked an opportunity to gather important health information for entire categories of racial and ethnic subgroups.

C. Federal COVID-19 Race and Ethnicity Data Collection Efforts

Second to passage of the ACA, the COVID-19 pandemic represented an unprecedented opportunity to address health inequities in the United States, especially through improved demographic data collection. On his first day in office, President Biden issued an Executive Order titled *Advancing Racial Equity and Support for Undeserved Communities Through the Federal Government* (“Order I”).⁹⁴ Order I acknowledges that “[m]any Federal data sets are not disaggregated by race, ethnicity, gender, disability, income, veteran status, or other key demographic variables. This lack of data has cascading effects and impedes efforts to measure and advance equity.”⁹⁵ Order I also establishes a Data Working Group, which is required to “study and



provide recommendations ... identifying inadequacies in existing Federal data collection programs, policies, and infrastructure across agencies, and strategies for addressing any deficiencies.”⁹⁶

Soon after, President Biden issued another order, *Ensuring an Equitable Pandemic Response and Recovery* (“Order II”), which appears to be an attempt to seriously address many of the data development recommendations first raised in the Minority Health Task Force’s 1985 Report.⁹⁷ Order II notes that “[t]he lack of complete data, disaggregated by race and ethnicity, on COVID-19 infection, hospitalization, and mortality rates, as well as underlying health and social vulnerabilities, has further hampered efforts to ensure an equitable pandemic response.”⁹⁸ Importantly, Order II establishes within HHS a COVID-19 Health Task Force (“COVID-19 Task Force”) charged with the responsibility of “provid[ing] specific recommendations to the President ... for mitigating the health inequities caused or exacerbated by the COVID-19 pandemic and for preventing such inequities in the future.”⁹⁹ Order II also directs federal agencies and the COVID-19 Task Force to: (1) develop recommendations for expediting data collection for communities of color; (2) develop longer-term recommendations to address data shortfalls; and (3) submit its recommendations to the President.¹⁰⁰

In addition to President Biden’s Executive Orders I and II, on March 17, 2021, the CDC announced, pursuant to the Coronavirus Response and Relief Supplemental

Appropriations Act, 2021, (P.L. 116-260), that the agency would provide \$2.25 billion in funding to improve state, local, and territorial public health infrastructures, including:

[G]rants to public health departments to improve testing and contact tracing capabilities; develop innovative mitigation and prevention resources and services; improve data collection and reporting; build, leverage, and expand infrastructure support; and mobilize partners and collaborators to advance health equity and address social determinants of health as they relate to COVID-19.¹⁰¹

This funding specifically targets state and local efforts to “[i]ncrease/improve data collection and reporting for populations experiencing a disproportionate burden of COVID-19 infection, severe illness, and death, to guide the response to the COVID-19 pandemic.”¹⁰²

However, even these efforts have amounted to almost no movement in the push for disaggregated race and ethnicity data collection. Nothing in the suite of data collection tools currently employed by the CDC obtains disaggregated race and ethnicity data.¹⁰³ Jurisdictional health departments report cases, deaths, and other COVID-19 information to the CDC using the “Human Infection with Coronavirus Disease 2019 (COVID-19) Surveillance Worksheet” (“Surveillance Worksheet”).¹⁰⁴ The CDC’s COVID-19 Vaccine Program requires any COVID-19 vaccine provider to collect demographic information from all COVID-19 vaccine recipients.¹⁰⁵

The V-safe mobile app allows vaccine recipients to report any negative side effects of COVID-19 vaccines to the CDC.¹⁰⁶ However, the Surveillance Worksheet, the COVID-19 Vaccine Program, and V-safe only collect the minimum race and ethnicity demographic data, as guided by 1997 OMB Standards, rather than the more detailed 2011 HHS Data Standards.¹⁰⁷ Moreover, HHS race and ethnicity data reporting requirements for laboratories and vaccination providers also mandate collection only in accordance with the 1997 OMB Standards.^{108,109}

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Evidence of the federal government’s ineffective data collection methods can be found in the glaring holes in the CDC’s race and ethnicity demographic data. CDC data indicated that racial and ethnic information is only available for 66% of COVID-19 cases reported to the CDC nearly two years into the pandemic.¹¹⁰ This data was also missing for about one-third of the more than 250 million people who have received at least one dose of the COVID-19 vaccine, as of April 2022.¹¹¹ As noted in the 1985 Report, racial and ethnic data integrity is lost when this information is not accurately reported for a significant proportion of the population.¹¹² Ultimately, the COVID-19 pandemic represents, perhaps, the biggest missed opportunity in the federal effort to establish disaggregated race and ethnicity data as the standard in health care.

D. State COVID-19 Race and Ethnicity Data Collection

Although the federal standards for race and ethnicity categories serve as a national guide for data collection, states, themselves, play a vital role in collecting demographic health data. In general, hospitals, providers, and laboratories are required to report disease incident to local public health jurisdictions pursuant to state law. Those laws mandate what information health care systems and providers are required to report to local public health jurisdictions.¹¹³ The data is then shared with the CDC and is the primary source of race and ethnicity data at the federal level.¹¹⁴ State data collection requirements are thus crucial in the effort to collect national race and ethnicity data.

Our March 2021 survey found that no state consistently published any COVID-19 data disaggregated by Latinx subgroups, and only one state (Hawaii) disaggregated data by Asian subgroups.¹¹⁵ In fact, some states, like

West Virginia and Florida, collected racial data for COVID-19 cases for only subgroups “white,” “Black,” “other,” and “unknown”—all Asian, Pacific Islander, and Native Hawaiian people are counted as “other.”¹¹⁶ Likewise, the District of Columbia used over-aggregated race categories on its COVID-19 vaccine dashboard.¹¹⁷ And Hawaii, North Dakota, and West Virginia did not collect any ethnicity data for COVID-19 cases.¹¹⁸

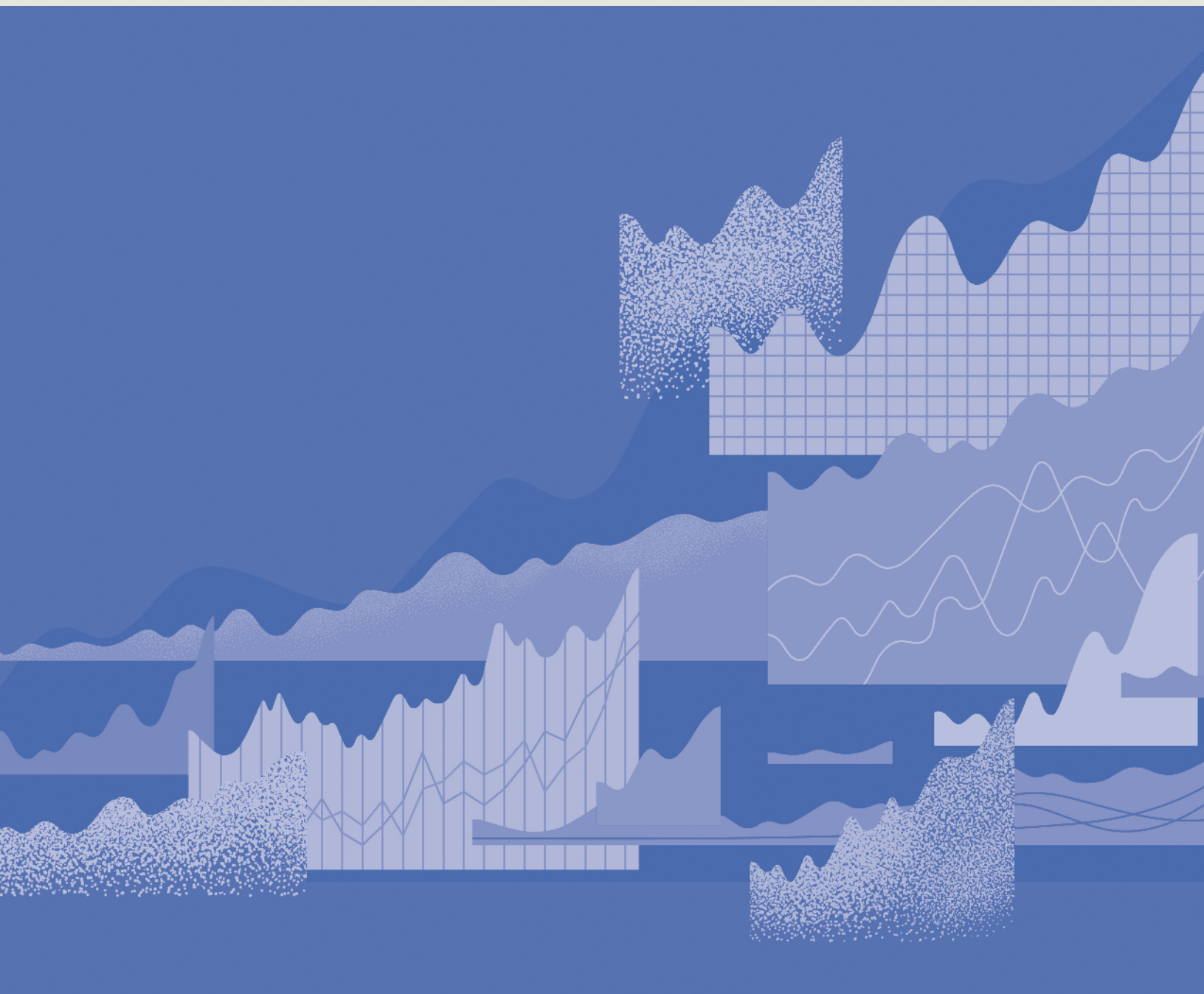
That states vary widely in their COVID-19 data collection practices is unsurprising. Lack of guidance from the federal government regarding data collection and

reporting at the pandemic’s onset meant states were left to develop their own data collection processes and tools. At this late stage, it is highly unlikely that states will adopt uniform data collection practices related to COVID-19. And unfortunately, just as the Minority Health Task Force found in 1985, “the lack of common practices among the [s]tates in recording ethnicity identifiers in their reported data” has resulted in a data shortfall.¹¹⁹ Because of the symbiotic relationship between state and federal data collection, this shortfall has persisted throughout the pandemic.



PART II

BEYOND RACE: OTHER METRICS FOR EQUITABLE DATA COLLECTION



Though disaggregated race and ethnicity data are critical to equitable data collection, truly comprehensive efforts must also include metrics reflecting a number of other indicators of health outcomes, especially in the context of the COVID-19 pandemic. For example, data tracking the distribution of health care resources, such as testing, treatment, and vaccination, is crucial to identifying barriers to health care and mitigating poor health outcomes among communities of color and other systemically marginalized groups. And, states generally do not track other important demographic metrics, ranging from housing to employment status, that can help mitigate the spread of disease among people most likely to become infected or severely sickened. As shown below, comprehensive health care information must be published alongside extensive demographic data to determine drivers of poor health outcomes and create a public health response that does not worsen disparities.¹²⁰

A. Gaps in Health Care and Health Status Data

Equitable data can identify health disparities driven by medical bias and the inequitable distribution of medical resources by health care systems and public health jurisdictions. Although most states reported at least some race and ethnicity data for cases, deaths,¹²¹ and vaccinations¹²² during the first year of the pandemic, public health jurisdictions failed to collect other critical health data. For example, just one state (Minnesota) published racial data on COVID-19 ICU patients, and only 24 states published racial data on hospitalized patients, despite commonly used CDC tools like the COVID-19 Surveillance Worksheet requesting some race and ethnicity information for hospitalized patients.¹²³ And, only 10 states published this data for testing, although laboratories that conduct COVID-19 tests are required to collect race and ethnicity data from patients.^{124,125}

Yet, testing and treatment data is critical to addressing health inequities, as racial health disparities are often

Equitable data can identify health disparities driven by medical bias and the inequitable distribution of medical resources by health care systems and public health jurisdictions.

linked to delayed screening and inadequate treatment.¹²⁶ As discussed below, comprehensive health care data is not only central to revealing racial health disparities, but also to identifying barriers to care and treatment.

i. Laboratory Testing Rates

In general, challenges in obtaining COVID-19 testing may mirror challenges in screening for various other diseases, such as cancer, diabetes, and heart disease—as communities of color, who are at highest risk for disease, are less likely to be screened and treated.¹²⁷ For example, Asian Americans are the least likely racial and ethnic group to receive recommended diabetes screening, even though this group is at high risk of



Type 2 diabetes.¹²⁸ Likewise, people of color receive cancer screening at lower rates than white people due to a number of barriers to accessing screening, including lack of knowledge, financial strains, and limited English proficiency.¹²⁹ COVID-19 testing disparities may, likewise, indicate a number of socio-economic or cultural barriers to testing for other conditions.

In general, challenges in obtaining COVID-19 testing may mirror challenges in screening for various other diseases, such as cancer, diabetes, and heart disease—as communities of color, who are at highest risk for disease, are less likely to be screened and treated.

Currently, COVID-19 case rate data, which all states and the CDC report, reflects positive COVID-19 lab tests only. However, demographic data that tracks all COVID-19 tests administered, as opposed to merely positive test results, is critical not only for tracking the spread of the virus, but also for identifying and dismantling barriers to health care screening resources. For example, at the pandemic's onset, the District of Columbia—whose population is 45.4% Black—did not set up free COVID-19 testing sites east of the Anacostia River, an area which consists of predominantly Black neighborhoods.¹³⁰ And, an early pandemic research brief by the Asian American Research Center on Health detailed that Asian Americans accounted for 52% of all deaths in San Francisco, despite comprising just 13.7% of cases.¹³¹

Some researchers have attributed this disparity to undertesting and a reluctance to get tested or seek care due to the racist stigmatization of Asian Americans surrounding the virus, especially those who look Chinese.¹³² Testing data therefore plays a critical role in mitigating poor health outcomes, as it allows public health jurisdictions, providers, and health care systems to equitably screen for disease based upon community need.

Yet, there is almost no testing data available. HHS and the CDC have implemented a reporting infrastructure for laboratories reporting testing data—an infrastructure that heavily relies on reporting by state and local public health jurisdictions. Section 18115 of the Coronavirus Aid, Relief, and Economic Security (“2020

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 HHS.¹³³ Each test result report must include demographic information like the patient's race, sex, and ethnicity.¹³⁴ And, though the CDC has ostensibly received this data for at least a substantial number of test recipients, the agency still has not published any testing data disaggregated by race and ethnicity.

It is important to acknowledge that the Health Resources and Services Administration (“HRSA”), a sub-agency of HHS, does publish the racial and ethnic breakdowns for COVID-19 tests reported by health centers in its “Health Center COVID-19 Survey.”¹³⁵ However, while the HRSA data is useful, it is still insufficient, as the survey covers only a minuscule proportion of tests administered, approximately 2.2% of the roughly 768 million tests that have been reported to the CDC.¹³⁶

At the state level, our survey shows that only 10 states collect and publish racial and ethnic demographic data for COVID-19 tests.¹³⁷ In July 2020, California, one of these states, issued an emergency regulation requiring that laboratories collect race/ethnicity information, and health care providers collect gender identity data in addition to the race/ethnicity information they are

At the **state level**, our survey shows



collect and publish racial and ethnic demographic data for COVID-19 tests.

already required to collect.¹³⁸ According to California's Health and Human Services Secretary, Dr. Mark Ghaly: "[i]mproving [this] data is like getting a new pair of glasses that helps us see more clearly," and helps to determine whether "state interventions are working and close disparities."¹³⁹

ii. Case Rates and Breakthrough Infection

It is now widely recognized that people of color are disproportionately infected with COVID-19, relative to their share of the population.¹⁴⁰ As noted in a recent U.S. Senate report, "Latinx people have experienced some of the highest rates of infection from COVID-19 in the country. Within the first three months of the pandemic, counties where more than a quarter of the population is Latinx saw infection rates increasing at higher rates than in counties with smaller Latinx populations, and as of July 2020, the infection rate among Latinx people was more than three times the rate among white patients."¹⁴¹ And, Black people faced infection rates three times that of their white counterparts. Though these disparities have been laid bare since the beginning of the pandemic, states report worse race and ethnicity data for COVID-19 cases than almost every other metric. As of April 2022, race and ethnicity data was reported for just 62.94% of cases reported, compared to 82% for deaths.¹⁴² Demographic case data is thus incomplete.

Furthermore, the effort to track infection rates in communities most impacted by COVID-19 has been frustrated by governmental action, even as the pandemic continues. First, the CDC announced in May 2021 that it would no longer track post-vaccination infection ("breakthrough infection") incidents among

The effort to track infection rates in communities most impacted by COVID-19 has been frustrated by governmental action, even as the pandemic continues.

the majority of the vaccinated population.¹⁴³ There is now limited data on COVID-19 breakthrough infection in instances of hospitalization or death. This data is reported by the CDC's COVID-NET network, which consists of 250 hospitals in just 14 states.¹⁴⁴ The CDC also tracks infection among vaccinated people living in long-term care settings, as well as some health care workers in eight U.S. cities.¹⁴⁵

Though the CDC continues to monitor breakthrough cases among all people, this data was only reported by 28 U.S. jurisdictions in January 2022.¹⁴⁶ There is no demographic data, other than age, for breakthrough infections through any reporting mechanism.¹⁴⁷ As more of the country becomes vaccinated, the case rate data may fail to highlight the spread of the disease, as well as the effectiveness of the vaccines among immunocompromised people and those living with underlying conditions.

Second, the federal program that provided free COVID-19 testing and vaccinations for uninsured people ended in April 2022, rendering testing as costly as \$125, and thus inaccessible for millions of people who are already disproportionately impacted by the pandemic.¹⁴⁸ Coupled with the rise in use of at-home tests, which are largely unreported, tracking case rates with any measure of accuracy will become significantly more challenging.

As of April 2022, the CDC received **race and ethnicity data** on



82.0%
of deaths

but only

62.9%
of infections



iii. Hospitalization Rates

Recent data published by the CDC indicated that American Indian or Alaskan Native people are still 3.1 times more likely than white people to be hospitalized after contracting COVID-19.¹⁴⁹ Black and Hispanic or Latinx patients are hospitalized at a rate 2.4 and 2.3 times higher than white patients, respectively.¹⁵⁰ These disparities are indicative of dual inequities at work. Black Americans, for example, disproportionately experience systemic socio-economic conditions (discussed further below) that render them more susceptible to diseases, such as diabetes, hypertension, asthma, and obesity. These conditions increase the likelihood of serious COVID-19 infections that may require hospitalization.¹⁵¹ These trends are exacerbated when the pandemic response effort excludes or does not adequately target aid to the communities that need it most.

Hospitalization data may also reveal disparate treatment of patients who present to emergency departments with COVID-19 symptoms. A bulletin entitled, “COVID-19 Like Emergency Department Visits by Race and Ethnicity,” data collected by the Virginia Department of Health, revealed that “non-Hispanic Whites showing up at EDs are being admitted at a higher rate than other races,” indicating that “health providers may take complaints by white patients more seriously than patients of color.”¹⁵² Hospitals are covered by civil rights laws that protect patients from discrimination, but it can be difficult to identify discriminatory practices without this data.

HHS and the CDC collect racial and ethnic demographic hospitalization data in four ways: (1) hospitals report directly to HHS/CDC pursuant to HHS regulations

governing hospital administrators;¹⁵³ (2) in certified states, hospitals report to the local/state/territorial/tribal public health authorities, who then report to HHS/CDC;¹⁵⁴ (3) hospitalization fields are listed on the CDC Case Report Form/Surveillance Worksheet utilized by jurisdictional/state health departments, who receive hospitalization information from local hospitals;¹⁵⁵ and (4) the federal COVID-19-Associated Hospitalization Surveillance Network (“COVID-NET”) analyzes and publishes this data directly from 250 hospitals in its network.^{156,157} Despite multiple reporting mechanisms, federal race and ethnicity demographic data is limited to COVID-NET hospitals, and none of the applicable HHS regulations require hospitals to report race and ethnicity information for COVID-19 patients.¹⁵⁸

Moreover, as noted above, just 24 states report race and ethnicity data for hospitalized patients. New Jersey, however, passed a law requiring hospitals to collect and report demographic data to the Department of Health—including age, ethnicity, gender, and race—for individuals who attempted to get treatment for COVID-19; were admitted for treatment for COVID-19; or attempted to get tested for COVID-19 but were refused.¹⁵⁹ Such information is necessary not only for tracking hospitalization, but also disparate treatment in health care.

Thus, it is imperative that HHS amend its guidance to require hospitals to report racial and ethnic demographic data for COVID-related hospitalizations.¹⁶⁰

iv. ICU Admissions Rates

Limited available data indicates that 21.1% of the non-Hispanic white people hospitalized due to COVID-19 were later admitted to the ICU—the lowest proportion of any racial group.^{161,162} American Indians and Alaska Natives have the highest percentage at 30.1%.¹⁶³ However, racial disparities in care and outcomes persist in the ICU. COVID-19 ICU demographic data can root out these inequities in critical care, especially when viewed in conjunction with fatality rates, which nearly all states publish by race and ethnicity.¹⁶⁴

Hospitals are covered by civil rights laws that protect patients from discrimination, but it can be difficult to identify discriminatory practices without this data.



Available research indicates that Black patients experience higher mortality rates than white people following ICU admission.¹⁶⁵ Along these same lines, patients of color are more likely to die from Acute Respiratory Distress Syndrome, which is associated with COVID-19 infection and managed in the ICU.¹⁶⁶ Moreover, patients at minority-serving hospitals—defined as hospitals with twice as many black or Hispanic patients as expected based on the percentage of those living in the region—may experience longer waits before being admitted to the ICU,¹⁶⁷ and Black patients in the ICU are less likely to receive timely antibiotics than white patients.¹⁶⁸

As ICU admissions data can provide a window into potentially fatal racial discrimination and inequities in hospitals, states and the federal government should

Available research indicates that Black patients experience higher mortality rates than white people following ICU admission.

ensure, through updated guidance, that hospitals include racial and ethnic demographic information for patients admitted to the ICU. Where already available, states and the CDC should make that data public. ICU admission information is currently listed as a field on the CDC's COVID-19 Surveillance Worksheet and (archived) Case Report form.¹⁶⁹ Yet the federal government has released only broad race and ethnicity demographic data related to ICU admissions from hospitals within the COVID-NET program.¹⁷⁰ States likewise fail to release this data; our survey indicates that only Minnesota reports this information.¹⁷¹

v. Health Insurance

Health insurance coverage plays an outsized role in individuals' ability to access quality health care for all diseases, including COVID-19 treatment. Yet, neither the CDC nor states publish insurance status or type for COVID patients, despite the critical role insurance plays in determining health outcomes. Demographic data on health insurance status and type in the COVID-19 context could help identify a range of patterns in barriers to health care access, as well as discrimination in health care.

Substantial racial and ethnic disparities exist with respect to health insurance coverage.¹⁷² Black and other systemically marginalized communities are insured at significantly lower rates than their white counterparts.¹⁷³ Census data reveals that 9.6% of Black and 16.7% of Hispanic people lacked health insurance in 2019, compared to 5.2% of non-Hispanic white individuals.¹⁷⁴ Moreover, low-income populations are more likely to lack health insurance coverage than those in higher income brackets.¹⁷⁵ Additionally, many uninsured adults are employed in service industries, like retail or food-service, where workers face a higher risk of exposure to COVID-19.¹⁷⁶

Available research shows that lack of health insurance even impacts people's utilization of free health care services. Indeed, a U.S. Census Bureau survey from March 2021 indicates that over six million people felt concerned about the cost of COVID-19 vaccines, roughly one-third of whom live in a household with an annual income below \$35,000—namely, those more likely to lack health insurance.¹⁷⁷ Some COVID-19 vaccine providers ask for health insurance information as part of the vaccine registration process, potentially confusing and dissuading low income, uninsured populations from signing up for a dose.¹⁷⁸

Insurance status data may also reveal whether uninsured populations, disproportionately communities of color, forgo potentially life-saving treatment due to cost. News reports indicate that people, particularly



those without insurance, may make crucial health care decisions out of fear of exorbitant medical bills.¹⁷⁹ This is unsurprising, as research shows that even small medical costs may cause people to delay treatment.¹⁸⁰ Because COVID-19 treatment can be prohibitively expensive—especially in severe cases requiring lengthy hospitalization—uninsured patients may delay or refuse care, leading to worse health outcomes.¹⁸¹ Armed with this information, public health officials and health care systems can develop more effective strategies and policies to ensure that cost does not deter uninsured and underinsured people from seeking vital COVID-19 health resources.

Finally, even some people with insurance may face an inability to access health care, as many physicians often refuse to see patients with Medicaid.¹⁸² For Medicaid patients who do receive care, one study showed that adults with Medicaid perceived more

Ultimately, national data on insurance status and type could reveal vast disparities in access and treatment in health care, especially when viewed in conjunction with other health care and personal identifier data, such as primary language, housing status, employment type, and sexual orientation and gender identity.

discrimination relative to their race or skin color than those with employer-sponsored insurance.¹⁸³ Medicaid patients also report less satisfaction with their health care in comparison to patients with other types of insurance.¹⁸⁴ Thus, patients with Medicaid may face additional barriers to health care that could dissuade them from seeking treatment for a variety of illnesses, including COVID-19.

Ultimately, national data on insurance status and type could reveal vast disparities in access and treatment in health care, especially when viewed in conjunction with other health care and personal identifier data, such as primary language, housing status, employment type, and sexual orientation and gender identity. Given the stark intersection of the pandemic with these identities, national and statewide health care resource data could support substantial efforts to address health inequities in the United States.

vi. Preexisting Conditions and Disability Status

There is no question that rectifying health disparities requires prioritizing the delivery of health care resources to communities most in need, which often means those most likely to suffer infection or severe illness. The CDC has identified five underlying medical conditions that increase the risk for severe COVID-19 associated illness.¹⁸⁵ Included in this list are several medical conditions that disproportionately affect communities of

color and other systemically marginalized communities. For example, the CDC notes that people who suffer from high blood pressure, obesity, and diabetes “can be more likely to get severely ill from COVID-19.”¹⁸⁶ These medical conditions are found in higher rates amongst African Americans than their white counterparts.¹⁸⁷ The CDC also found that smokers (current or former) and those who are HIV positive are also at an increased likelihood of severe COVID-19 illness.¹⁸⁸

There is no question that rectifying health disparities requires prioritizing the delivery of health care resources to communities most in need, which often means those most likely to suffer infection or severe illness.

Likewise, the COVID-19 pandemic has also disproportionately impacted people living with disabilities. A study of 64 million patient records revealed that those with intellectual disabilities are 2.5 times more likely to be infected with COVID-19, 2.7 times more likely to be hospitalized, and 5.9 times more likely to die from COVID-19.¹⁸⁹ The study’s authors noted that an intellectual disability was “the strongest independent risk factor for presenting with a COVID-19 diagnosis and the strongest independent risk factor other than age for COVID-19 mortality.”¹⁹⁰ Preexisting condition and disability status data is thus a necessary tool for the equitable delivery of

Relative to the general population, a study of 64 million patient records revealed that those with **intellectual disabilities** were more likely to suffer

2.5 x



infection with COVID-19

2.7 x



hospitalization with COVID-19

5.9 x



mortality from COVID-19



health care, which requires the prioritization of groups more likely to face severe illness and death to receive resources, including vaccines and testing.

The CDC currently publishes data on comorbidities recorded in conjunction with COVID-19-related deaths,¹⁹¹ and also provides county-level, model-based estimates of the prevalence for each of the five underlying conditions that increase risk for severe COVID-19-associated illness.¹⁹² However, less than half of states publish the rates of COVID-19 among people with comorbidities or their outcomes.¹⁹³ Among the states that do, some, like Arizona, do not disaggregate by type of comorbidity.¹⁹⁴

Moreover, as noted above, Sec. 4302 of the ACA requires that all federally-funded public health activities collect disability status information from participants.¹⁹⁵ Although the CDC collects this information on its Case Report Form/Surveillance Worksheet, neither the CDC nor HHS collects this information in other important COVID-19 surveillance activities.¹⁹⁶ HHS does not, for example, require providers to report disability information for COVID-19 vaccinations nor does the agency list disability status as a required data element in its Laboratory Data Reporting Guidance.¹⁹⁷ Likewise the CDC's V-safe does not request disability information from vaccine recipients.¹⁹⁸ Thus, there is a dearth of

data describing the full impact of COVID-19 upon people living with disabilities, and additional effort is required at both the state and federal level.

vii. Pregnancy Status

The CDC has determined that COVID-19 presents serious risks to pregnant people. According to the CDC:

Pregnant and recently pregnant people are at an increased risk for severe illness from COVID-19, compared with non-pregnant people. Severe illness includes illness that requires hospitalization, intensive care, need for a ventilator or special equipment to breathe, or illness that results in death. Additionally, pregnant people with COVID-19 are at increased risk of preterm birth and might be at increased risk of other adverse pregnancy outcomes, compared with pregnant women without COVID-19.¹⁹⁹

Pregnancy status is thus a data point critical to the development of a targeted public health strategy that reaches people living at the intersection of multiple marginalized identities. For example, prior to the pandemic, the U.S. had the highest maternal mortality rate among developed countries.²⁰⁰ For non-Hispanic Black women specifically, the maternal mortality rate is 2.5 times higher than their non-Hispanic white counterparts²⁰¹ and experts anticipate “that maternal mortality among Black women in the U.S. ... will increase further during the coronavirus pandemic.”²⁰²

However, there is limited data on pregnant people who test positive for COVID-19. Though the CDC reported in January 2022 that there had been 166,935 COVID-19 cases

Pregnancy status is thus a data point critical to the development of a targeted public health strategy that reaches people living at the intersection of multiple marginalized identities.

reported among pregnant women, only one-third of case report forms used throughout 56 jurisdictions include information on pregnancy status.²⁰³ And, although the CDC reports race and ethnicity data for pregnant women, this data is incomplete, as it was only available for 87.5% of women.²⁰⁴ Moreover, the CDC reports data for pregnant women hospitalized with COVID-19; admitted to the ICU; and those requiring invasive ventilation or ECMO.²⁰⁵ However, data is available for only 10.6%, 7.7%, and 8.1% of pregnant women requiring ICU admission, invasive ventilation, and ECMO, respectively.²⁰⁶ As such, data on the severity of COVID-19 infection in pregnant women is severely underreported. Moreover, the CDC does not report the race or ethnicity of women hospitalized or those provided with intensive care, so it is impossible to determine whether pregnant women of color face worse outcomes than white women. The data likely also does not fully encompass all people who can get pregnant, particularly transgender men and nonbinary individuals, since CDC pregnancy data uses language that focuses on “female[s].”²⁰⁷

The CDC also reports vaccination data among pregnant women, but this data is also limited. Vaccination data for pregnant women is collected only from its Vaccine Safety Datalink network, which consists of

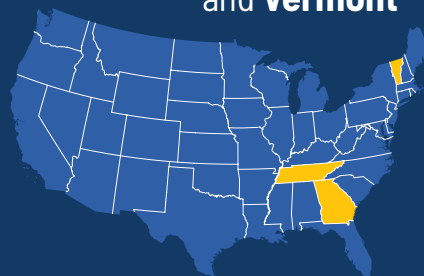
nine integrated health care organizations in just seven U.S. states.²⁰⁸ Although the CDC reports some race and ethnicity data for vaccinated pregnant women, this data is even more limited than the OMB categories and include only “Black,” “White,” “Hispanic/Latino,” “Asian,” and “other.”²⁰⁹

Moreover, real work needs to be done at the state level. Only Tennessee, Georgia, and Vermont have published pregnancy data related to COVID-19, and the amount of detailed information varies between these three states.²¹⁰ In November 2020, Tennessee published a short report on COVID-19 pregnancy data broken down by race and ethnicity.²¹¹ Vermont published limited pregnancy data, listing it as one of several “preexisting conditions” that the state is tracking in some, but not all, of its weekly COVID-19 summaries.²¹² Georgia published pregnancy data in its COVID-19 Daily Status Report, tracking pregnancy as a comorbidity in its *Confirmed COVID-19 Cases with Comorbidity Status by Race and Sex* data table.²¹³

Because of the outsized potential for the maternal mortality crisis to worsen, especially among Black women, all states should collect and publish data on pregnancy status related to COVID-19.



Only **Tennessee, Georgia,**
and **Vermont**



have published **pregnancy data**
related to COVID-19, and the amount
of detailed information **varies** between
these three states.

B. Socio-Economic and Intersectional Data

Health disparities, including those caused or exacerbated by the pandemic, exist across socio-economic strata and among those who live at the intersections of multiple marginalized identities. Together with health and disaggregated race and ethnicity data, these data points represent the best COVID-19 data collection practices. The inclusion of these additional markers would provide states and the federal government with the opportunity to develop more comprehensive health interventions for people “living at the margins of our economy.”²¹⁴

i. Primary Language

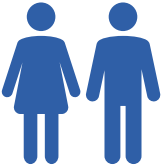
The Minority Health Task Force reported in 1985 that “cultural differences and language difficulties are major barriers for immigrants and refugees for using existing health services in the areas where they reside.”²¹⁵ Research shows that those with limited English proficiency have greater difficulty utilizing medical services and, when they do seek care, often receive lower quality treatment.²¹⁶ To reveal and reduce the impact of language barriers upon health outcomes, data related to the patient’s primary language must be collected and published. An investigation by Brigham and Women’s Hospital in Boston found that language played a significant role in patients’ risk of dying from COVID-19 early on in the pandemic: while Hispanic, non-English speaking patients had a 35% higher risk of death from COVID-19 compared to the total patient population,

there was no such increased risk for Hispanic patients who spoke English.²¹⁷ National data is needed to assess the extent to which language barriers could contribute to high COVID-19 case rates and poor health outcomes among limited English proficiency populations, who may struggle to access prevention, testing, and treatment information.²¹⁸

Health disparities, including those caused or exacerbated by the pandemic, exist across socio-economic strata and among those who live at the intersections of multiple marginalized identities.

Though required by Sec. 4302 of the ACA and highlighted in the 2011 HHS Data Standards, federal data collection tools do not consistently track this critical language information. V-safe, for example, does not collect primary language data.²¹⁹ In neither HHS’s *COVID-19 Pandemic Response, Laboratory Data Reporting: CARES Act Section 18115* guidance nor the CDC’s *Comprehensive Vaccine Data Requirements* do the agencies mention the collection of primary language data.²²⁰ And because many of these federal COVID-19 tools do not collect language data, the federal government is largely unaware of the ways that language barriers have impacted non-English proficient populations during the pandemic.²²¹

Compared to the
total patient population,



**Hispanic, non-English
speaking** patients had a



35%
higher risk of
death from
COVID-19



ii. Sexual Orientation and Gender Identity

The Office of Disease Prevention and Health Promotion (ODPH)—a part of HHS—has recognized that health disparities exist between the Lesbian, Gay, Bisexual, Transgender, Queer/Questioning, Intersex, and Asexual (“LGBTQIA”) community and people who do not hold these identities. As described by the Center for American Progress, members of the LGBTQIA community have lower rates of health insurance, high rates of stress due to systemic discrimination and harassment, and experience a lack of cultural competency by health care providers—all of which culminate into health disparities between their heterosexual counterparts. Yet, according to ODPH, “[s]exual orientation and gender identity questions are not asked on most national or State surveys, making it difficult to estimate the number of LGBT individuals and their health needs.... [There is a] need for more research to document, understand, and address the environmental factors that contribute to health disparities in the LGBT community. As part of this work, we need to increase the number of nationally representative health-related surveys that collect information on sexual orientation and gender identity (SOGI).”²²²

Yet, no federal COVID-19 data surveillance tool requests this information,²²³ even though all electronic health record systems certified by the federal government’s Health IT Certification Program must have the capacity to capture a patient’s sexual orientation and gender identity.^{224,225} One year into the pandemic, Rhode Island and California were the only states that tracked and published the spread of COVID-19 according to sexual orientation and/or gender identity, our survey revealed.²²⁶

Collection of this information is crucial because LGBTQIA people have been, and continue to be, denied access to medical services or face other forms of discrimination when seeking care.²²⁷ Yet, due to higher rates of comorbidities, the LGBTQIA community is at heightened risk for severe COVID-19 outcomes.²²⁸ In fact, a February 2021 CDC report found that “sexual minority persons”—those whose sexual orientation, gender identity, or sexual characteristics are different

Members of the LGBTQIA community have lower rates of health insurance, high rates of stress due to systemic discrimination and harassment, and experience a lack of cultural competency by health care providers.

from the presumed majority of the population—have higher rates of asthma, heart disease, cancer, and chronic kidney disease than “heterosexual” individuals—all conditions associated with more severe COVID-19 illness.²²⁹

And these disparities are heightened for people of color within the LGBTQIA community. A report by the Williams Institute determined that, during the fall 2020 coronavirus surge, LGBT people of color were twice as likely to test positive (14.5%) compared to their white LGBT counterparts (7.2%) *and* more likely to test positive than non-LGBT minority individuals (10.6%).²³⁰ The CDC itself has noted that including sexual orientation and

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compared to their
white LGBT counterparts (7.2%)
and more likely to test positive than
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minority individuals (10.6%)



gender identity data in COVID-19 surveillance efforts “could improve knowledge about disparities in infections and adverse outcomes among sexual and gender minority populations, overall and by race/ethnicity.”²³¹

Moreover, unemployment and poverty are inextricably linked to worse health outcomes.²³² For instance, adults with an income four or more times the federal poverty level live roughly seven to eight years longer than those living in poverty.²³³ These socio-economic factors compound the impact of COVID-19 on LGBTQIA people, who face significantly higher rates of poverty than the general population (21.6% versus 15.7%) according to a 2019 study.^{234,235} Transgender and nonbinary people of color, who are unemployed at up to four times the rate of the general population, are particularly susceptible to economic instability.²³⁶ And as a result of the

Transgender and nonbinary people of color, who are unemployed at up to four times the rate of the general population, are particularly susceptible to economic instability.

economic fallout of the pandemic, these communities risk falling deeper into poverty.²³⁷ For those who have remained employed, LGBTQIA and nonbinary people are more likely to work in industries that put them at greater risk of contracting the virus.²³⁸

Because of these combined factors, the LGBTQIA and nonbinary community is likely at higher risk of developing health complications, including those associated with the virus. Collecting sexual orientation and gender identity data can assist experts in designing interventions that address these factors that result in inequities in the LGBTQIA community.

iii. Employment Status and Income

As noted by one study, “negative exposures in the workplace that can harm health ... ‘get under the skin’ to affect health in a variety of ways, ranging from inhalation of dust or physical contact with toxins to changes in levels of hormones in the body in response to stress.”²³⁹ The pandemic has made clear the relationship between negative exposures in the workplace and health. For many, employment can serve to increase one’s likelihood of COVID-19 exposure, while simultaneously acting as a barrier to vaccination. The pandemic has disproportionately affected workers in front-line and essential jobs.^{240,241} A large-scale study found that essential workers in Philadelphia had a 55% higher chance of contracting COVID-19 than people who could work from home last spring.²⁴² And according to the Brookings Institution, almost half of all low-income workers have been considered essential workers during the pandemic.²⁴³

Along the lines of race, “[B]lack and Latino Americans make up a large part of the essential workforce and have been disproportionately affected by COVID-19.”²⁴⁴ The Center for Economic and Policy Research (“CEPR”) found that Black people, for example, make up about 12% of the U.S. workforce but represent 17% of front-line workers.²⁴⁵ In New York City, which was ravaged by the virus early on in the pandemic, 75% of front-line workers are people of color.²⁴⁶ Women are likewise disproportionately represented in front-line work according to the CEPR, constituting 64.4% of front-line workers but only 47.4% of the national workforce.^{247,248} Despite the pandemic’s disproportionate impact on front-line and essential workers, Washington and Iowa were the only states that reported employment status

A large-scale study found that essential workers in Philadelphia had a 55% higher chance of contracting COVID-19 than people who could work from home last spring.

data a year into the pandemic.²⁴⁹ And in Washington, about half of cases (43%) were missing employment data in one report.²⁵⁰

Worse still, recent reports reveal that essential workers, in particular, may be unable to take time off to get vaccinated.²⁵¹ A 2021 Kaiser Family Foundation study reported that 54% of unvaccinated, employed Hispanic adults polled would be more likely to get a COVID-19 vaccine if their employer gave them paid leave to get and recover from the vaccine.²⁵² This problem is so serious that New York recently passed a law requiring employers to provide employees with four hours of leave (which cannot be deducted from vacation or sick leave) to receive a COVID-19 vaccination.²⁵³

As to household income, California is the only state to publish detailed data related to the COVID-19 pandemic and income.²⁵⁴ There, the state utilizes income data to track community case rates. California's analysis found that communities with a median annual household income of less than \$40,000 had among the highest rates of COVID-19 cases (3.1 cases per 100,000 people) while communities with a median income

of \$120,000 or more had the lowest case rate for any income bracket (1.3 cases per 100,000 people).²⁵⁵

This is significant because low-income populations have a higher risk of severe illness if infected with COVID-19. One issue brief published early in the pandemic found a 35% chance of severe illness for those in households with less than \$15,000 in income, while only 16% for individuals in households earning over \$50,000.²⁵⁶ Low-income individuals have higher incidence of chronic conditions, a known risk factor for severe illness and death with respect to COVID-19.²⁵⁷ Moreover, low-wage workers are less likely to be able to work from home than higher earners, and therefore more likely to be exposed to COVID-19 while on the job.²⁵⁸ And when they do get sick, those in low-income communities are also less likely to have access to adequate health care resources, like ICU beds, which may result in poorer health outcomes for low-income people.²⁵⁹ Given that low-income populations face these outsized risks of infection and death from COVID-19, thorough data collection is needed to understand the true impact of COVID-19 on low-wage workers, ensure an equitable distribution of medical resources by federal and state authorities, and inform public health efforts in low-income communities.

iv. Housing Status and Type

An individual's housing status and/or type are strongly correlated with health disparities. Studies show that unhoused people suffer substantially worse physical



In New York City, which was ravaged by the virus early in the pandemic,

75% of frontline workers are people of color



An individual's housing status and/or type are strongly correlated with health disparities.

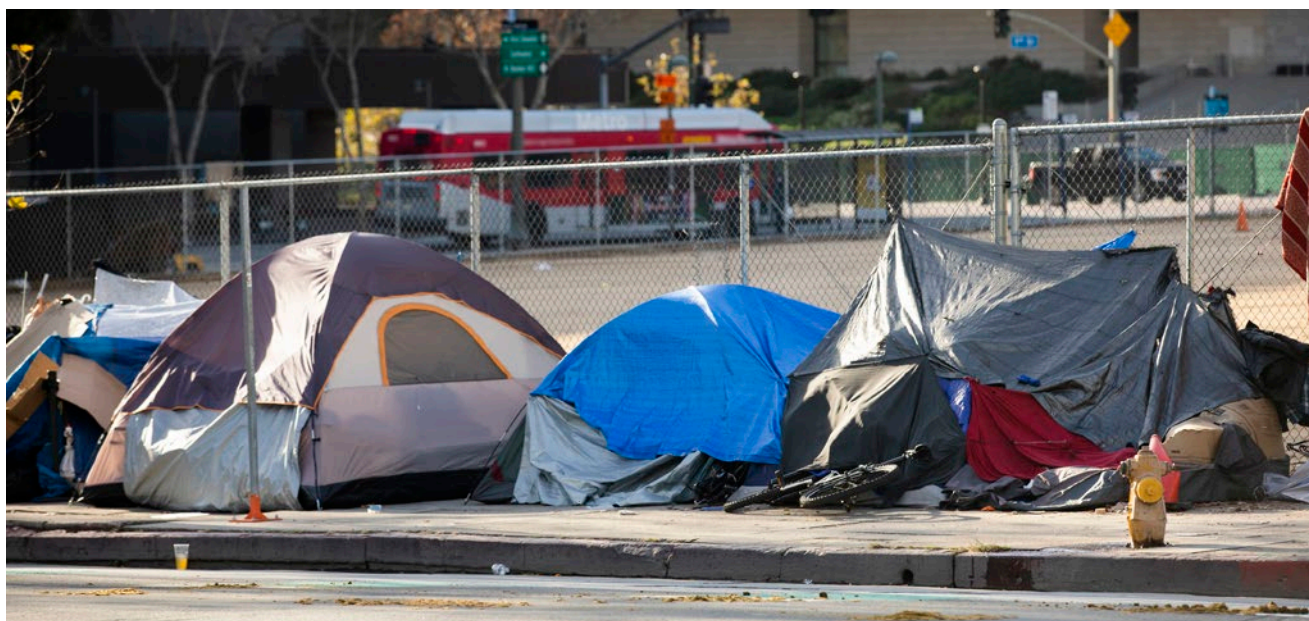
and mental health and increased mortality rates.²⁶⁰ People who face housing instability are, similarly, more likely to experience poor health in comparison to stably housed peers.²⁶¹ And, environmental factors within homes are correlated with poor health:

In-home exposure to lead irreversibly damages the brains and nervous systems of children. Sub-standard housing conditions such as water leaks, poor ventilation, dirty carpets, and pest infestation have been associated with poor health outcomes, most notably those related to asthma. Additionally, exposure to high or low temperatures is correlated with adverse health events, including cardiovascular events—particularly among the elderly. Residential crowding has also been linked to both physical illness (for example, infectious disease) and psychological distress.²⁶²

Certain types of housing are also correlated with higher COVID-19 infection rates. For example, data

reported in April 2021 showed that 32% of COVID-19 deaths occurred in nursing homes or other long-term care facilities.²⁶³ In New York, sheltered homeless people died of COVID-19 at a rate 49% higher than the New York City rate.²⁶⁴ Densely populated states, especially, should adopt the practices and procedures adopted by California, which is the only state that tracks COVID-19 risk factors like “crowded housing.”²⁶⁵ Minnesota also reports the housing status of COVID-19 patients, tracking whether a patient lives in a private residence, long-term care facility, jail/correctional facility, residential/behavioral health facility, work dorm, hotel, homeless shelter, homeless non-shelter, or a university.²⁶⁶

This information may be particularly valuable as studies have shown that younger people who live in multigenerational homes are at risk of transmitting the virus to older members of the household.²⁶⁷ And, according to a study by the Pew Research Center, Asian, Hispanic, and Black people are more likely to live in multigenerational households than white residents in the United States.²⁶⁸ As housing data can be critical for determining and mitigating the risk of infection faced by people who are unhoused or experience housing instability, more states should follow suit.



PART III

DATA COLLECTION CHALLENGES AND RECOMMENDATIONS FOR EQUITABLE DATA COLLECTION



A. Barriers to Equitable Data Collection

Collecting equitable health data is not merely a matter of will. According to a PolicyLink report, better data collection requires more resources and more funding:

For population surveys, the detailed enumeration of racial and ethnic subgroups can be an expensive and complex operation. Asking more questions and reaching more people both require more resources. Better pretesting, larger and more stratified samples, surveys administered in more languages, additional items in limited questionnaire space, greater outreach efforts to hard-to-contact households, more diverse and culturally competent staff, and more sophisticated coding to integrate previously unrelated databases are all improvements that will take larger budgets to be realized... Limited and fluctuating funding have so far prevented many state and local health surveys and ethnic health equity organizations from maintaining the high-quality and longitudinal data sets necessary to understand disparities faced by smaller groups.²⁶⁹

Collecting equitable health data is not merely a matter of will.

In addition to financial restraints, there is a widespread insufficiency of data collection infrastructure, which depends upon multilayered networks of providers and computer systems across varying health care systems. Many health care systems and facilities face technological challenges to collecting demographic information. Numerous facilities are under-resourced—particularly those serving lower-income communities—given Medicaid’s low reimbursement rates. These facilities simply do not have the health information technology (“IT”) infrastructure to gather and report this information.

Specifically, many providers utilize multiple data systems and face challenges linking data between systems.²⁷⁰ For example, a provider may have one system that tracks their patients’ records, including their demographic data, and a second system to send requests to medical laboratories, which is not set up to import demographic data from the first. In other instances, some outdated health IT systems are unable



to collect responses because the requisite forms are not built into the system or there is insufficient space for demographic information on collection forms.²⁷¹

Although Congress has mandated laboratories to report demographic data for COVID-19 tests, poor infrastructure continues to hamper demographic data collection during the pandemic. Laboratories generally rely on health care workers, such as nurses and physicians, to collect patient demographic data during testing. However, because of incompatibility between different electronic records systems, or because providers are not collecting that information in the first place, the data is not transmitted. This is exacerbated because of the dispersed nature of testing, occurring everywhere from drive-thru neighborhood sites to hospital ICUs. And, during a state of emergency, collecting robust demographic data may fall as a priority in favor of quicker test processing, particularly when doing so would require updating infrastructure.

Although Congress has mandated laboratories to report demographic data for COVID-19 tests, poor infrastructure continues to hamper demographic data collection during the pandemic.

Beyond this, health care provider or testing site operator shortfalls often drive poor data collection for several reasons. First, many providers fail to recognize the importance of collecting race and ethnicity data, deprioritizing it to speed up the time it takes to conduct patient intake. Providers also may not collect this information because of the patient's or their own personal discomfort with providing or seeking this information. Moreover, health care workers, or the institutions they work in, may simply fail to implement the technology and processes needed to collect demographic information. Finally, demographic forms used by providers may not adequately reflect the race or ethnicity of the patient.

Moreover, states, localities, public health entities, providers, and testing sites may have certain privacy concerns, misunderstandings, or low awareness of what personal data may be collected and shared for public health purposes under the Health Insurance Portability and Accountability Act.²⁷²

Finally, members of the public may not wish to provide this information due to mistrust of governmental or health care entities, particularly due to a long history of racism in the medical and scientific fields. This distrust is exacerbated when resources are not distributed during the pandemic in an equitable way to their communities.

Illinois provides an example of a multipronged approach to collecting demographic data on testing and infections. First, the state has directed testing facilities to collect data in accordance with the Illinois Control of Communicable Diseases Code, which requires a lab to report patient demographic information.²⁷³ Second, the state worked directly with labs to educate them on the necessity of collecting this data. The state has also educated the public on the importance of providing this information. Illinois also works to backfill this information where possible using other sources, such as death certificates. And, simply enough, the state encourages the use of forms that provide a section for patients to fill out their demographic information.



B. Recommendations for Equitable Data Collection

The Minority Health Task Force's 1985 Report made several specific recommendations to “enhance the opportunities for more effective data collection relating to minorities in the United States.”²⁷⁴ In particular, the report recommended standardizing ethnic identifiers; training personnel in the reporting of racial/ethnic identifying terms; establishing a mechanism to evaluate data quality; and a requirement that all HHS agencies that collect health data from individuals include racial and

ethnic identifiers, as defined by OMB, and record “further breakdown within racial and ethnic categories.”²⁷⁵ These recommendations are still relevant today. In light of the sustained attention demographic data collection has received since the onset of the pandemic, the federal government, states, local jurisdictions, and territories must coordinate to ensure authorities, physicians, and other experts can formulate a robust data-driven public health strategy to address health disparities resulting from the pandemic and beyond. Key actors and policy-makers at various levels of industry and federal, state, and local government must take the following actions:



Congress should:

- Authorize funds to provide testing, vaccination, and treatment for uninsured people. Without funding, people most likely to be infected will be the least likely to obtain care. Consequently, there will be a dearth of data pertaining to these populations.



At the federal level, HHS should issue guidance:

- Clarifying that all COVID-19 data collection tools should collect race, ethnicity, primary language, and disability information per the 2011 HHS Data Standards for public health surveys, pursuant to its authority under Sec. 4302 of the Affordable Care Act.
- Directing labs, health care providers, and hospitals to collect COVID-19 health care and health outcome data, disaggregated by race and ethnicity, in each of the following categories: (1) COVID-19 tests administered; (2) hospitalization rates; (3) ICU admissions; (4) comorbidities; (5) disability status/type; (6) insurance status; and (7) pregnancy status.
- Directing health care entities, including laboratories, hospitals, health care providers, and vaccine providers, to collect, report, and publish demographic COVID-19 data in each of the following categories: (1) sexual orientation and gender identity; (2) employment type and income; and (3) housing status.



HHS and the CDC should:

- Provide training to health care providers on equitable data collection practices, in conjunction with state and local public health departments. The outcomes of this training should be to increase the rates at which providers collect demographic data and the quality of that data, as well as to develop strategies for overcoming hesitations communities may have in providing demographic information.
- Develop and distribute standardized COVID-19 case forms that include sufficient space for demographic data collection. These forms should collect, at minimum, the 14 race and five ethnicity categories specified by the 2011 HHS Data Standards, pursuant to HHS's authority under Sec. 4302 standards. The forms should also provide space for collecting the remaining demographic categories specified above, to the extent those categories are not already included.
- Ensure that all COVID-19 data collected directly by the federal level through programs such as V-safe and FEMA-run vaccination sites, is disaggregated according to the 2011 HHS Data Standards, pursuant to its express authority under Sec. 4302 of the Affordable Care Act.
- Provide funding and technical assistance to ensure health information technology systems upgrades can happen as quickly as possible.



At the state/local/territorial level, public health authorities should:

- Require health care entities within their jurisdiction to collect COVID-19 health care and health outcome data disaggregated by race and ethnicity in each of the following categories: (1) COVID-19 tests administered; (2) hospitalization rates; and (3) ICU admissions.
- Provide raw COVID-19 data that would allow non-state-affiliated organizations to create their own databases and presentations of data that may better reach their relevant communities.
- Engage in direct one-on-one educational efforts with laboratories and providers regarding the collection of demographic data, especially for entities that fail to regularly report this data.
- Conduct public education campaigns regarding the importance of providing demographic information, including culturally and linguistically appropriate information provided to people to whom tests are administered.



Public health authorities, health care providers, hospitals, vaccine providers and laboratories must:

- Upgrade outdated health information technology systems throughout the entire data supply chain. All systems should collect detailed demographic data that are in line with the standards developed by the Office of the National Coordinator for Health IT and must be interoperable.
- Collect COVID-19 data on (1) sexual orientation and gender identity; (2) comorbidities; (3) employment type and income; (4) pregnancy status; (5) housing status; (6) hospitalization rates; (7) ICU admissions; (8) disability status/type; and (9) insurance status.



CONCLUSION

The consequences of the COVID-19 pandemic have largely mirrored the devastating effects of systemic health inequities that have plagued communities of color and other systemically marginalized groups in the United States for centuries. Because of its widespread effects throughout society, the pandemic represents a unique opportunity to finally right the wrongs formally identified by the United States government nearly 40 years ago. At that time, the federal government recognized “it was evident that to bring the health of minorities to the level of all Americans, efforts of monumental proportions were needed,” and also highlighted the critical role of comprehensive data in such an effort.²⁷⁶

The available COVID-19 demographic data has highlighted the disproportionate impact of the pandemic on systematically marginalized communities. But this

data is overly broad, at best, and often fails to capture the pandemic’s effects on subgroups within major categories of people. It is therefore imperative that federal, state, and local governments actively work to enhance and expand demographic data collection efforts. To do so, the federal government must coordinate with state, local, and territorial jurisdictions and require the collection of disaggregated race and ethnicity data through its own data channels, as well as other demographic data that can help mitigate the effects of the pandemic on a wide swath of people most likely to face infection, severe illness, and death.

Ultimately, anything other than a multi-pronged, highly coordinated approach among key players will result in a continued inability to accurately track health disparities, as inequities become more deeply entrenched in our health care system.

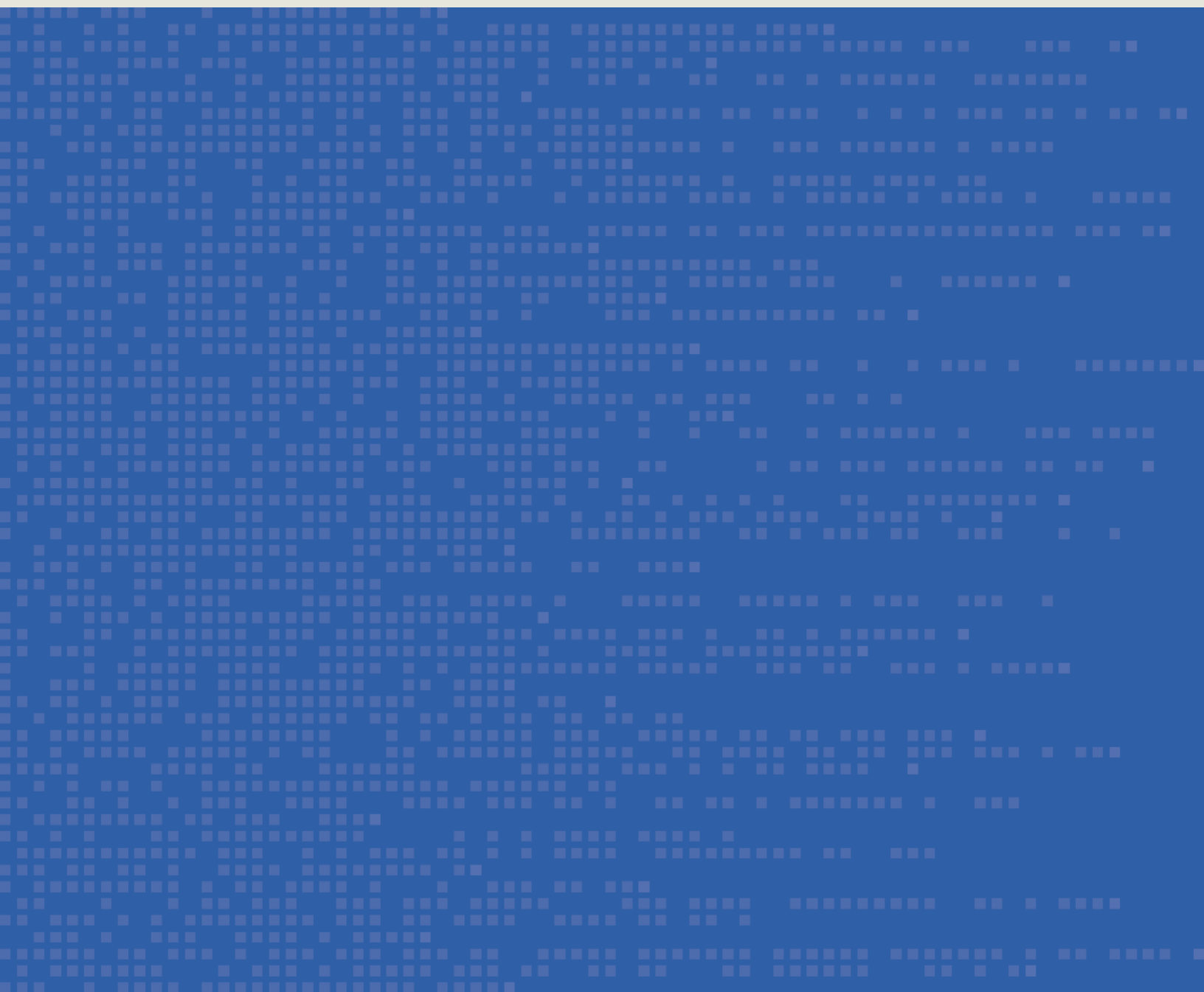
APPENDIX

DEMOGRAPHIC DATA TRACKER

FOR COVID-19

(last updated 03/18/2021)

This chart tracks publicly available data published on State COVID-19 websites/dashboards.



RACE AND/OR ETHNICITY

State	Cases	Hospitalization	ICU	Testing	Deaths	Vaccinations
Alabama	X				X	X
Alaska	X	X			X	X
Arizona	X	X			X	X
Arkansas	X				X	X
California	X			X	X	X
Colorado	X	X			X	X
Connecticut	X				X	X
DC	X			X	X	X
Delaware	X			X	X	X
Florida	X	X		X	X	X
Georgia	X	X			X	X
Hawaii	X	X			X	X
Idaho	X				X	X
Illinois	X			X	X	X
Indiana	X			X	X	X
Iowa	X				X	X
Kansas	X	X		X	X	X
Kentucky	X				X	X
Louisiana	X				X	X
Maine	X	X			X	X
Maryland	X				X	X
Massachusetts	X	X			X	X
Michigan	X				X	X
Minnesota	X	X	X		X	X
Mississippi	X				X	X
Missouri	X				X	X
Montana	X				X	
Nebraska	X	X			X	X
Nevada	X			X	X	X
New Hampshire	X	X			X	
New Jersey	X	X			X	X
New Mexico	X					X
New York					X	X
North Carolina	X	X			X	X
North Dakota	X					X
Ohio	X	X			X	X
Oklahoma	X				X	X
Oregon	X	X			X	X
Pennsylvania	X				X	X
Rhode Island	X	X		X	X	X
South Carolina	X	X			X	X
South Dakota	X	X			X	
Tennessee	X	X			X	X
Texas	X				X	X
Utah	X	X		X	X	X
Vermont	X	X		X	X	X
Virginia	X	X			X	X
Washington	X	X			X	X
West Virginia	X				X	X
Wisconsin	X	X			X	X
Wyoming	X				X	
Total	50	24	1	11	49	47

This chart does not track whether ethnicity is counted as a mutually exclusive race category or ethnicity data is collected separately from race data. It also doesn't track whether both race and ethnicity are reported for each category.

SEX

State	Cases	Hospitalization	ICU	Testing	Deaths	Vaccinations
Alabama	X				X	X
Alaska	X	X			X	X
Arizona	X	X			X	X
Arkansas	X					
California	X				X	X
Colorado	X	X			X	X
Connecticut	X				X	X
DC	X				X	X
Delaware	X				X	X
Florida	X			X	X	X
Georgia	X				X	
Hawaii	X	X			X	
Idaho	X				X	X
Illinois	X			X	X	X
Indiana	X			X	X	X
Iowa	X			X	X	X
Kansas	X				X	X
Kentucky	X				X	X
Louisiana	X				X	X
Maine	X	X			X	X
Maryland	X				X	X
Massachusetts	X	X			X	X
Michigan	X				X	X
Minnesota	X	X	X	X	X	X
Mississippi	X				X	
Missouri	X				X	X
Montana	X				X	
Nebraska	X	X			X	X
Nevada	X			X	X	X
New Hampshire	X	X		X	X	
New Jersey	X	X			X	X
New Mexico	X					
New York	X				X	
North Carolina	X	X			X	X
North Dakota	X					
Ohio	X	X			X	X
Oklahoma	X				X	X
Oregon	X	X			X	X
Pennsylvania	X				X	X
Rhode Island	X	X		X	X	
South Carolina	X	X			X	X
South Dakota	X	X			X	X
Tennessee	X	X			X	X
Texas	X				X	X
Utah	X	X			X	X
Vermont	X			X	X	X
Virginia	X	X			X	X
Washington	X	X			X	
West Virginia	X			X	X	X
Wisconsin	X				X	X
Wyoming	X				X	
Total	51	20	1	10	48	39

AGE

State	Cases	Hospitalization	ICU	Testing	Deaths	Vaccinations
Alabama	X				X	X
Alaska	X	X			X	X
Arizona	X	X		X	X	X
Arkansas	X				X	
California	X				X	X
Colorado	X	X			X	X
Connecticut	X				X	X
DC	X				X	X
Delaware	X				X	X
Florida	X	X		X	X	X
Georgia	X	X			X	X
Hawaii	X	X			X	X
Idaho	X	X			X	X
Illinois	X			X	X	X
Indiana	X			X	X	X
Iowa	X	X		X	X	X
Kansas	X	X		X	X	X
Kentucky	X				X	X
Louisiana	X				X	X
Maine	X				X	X
Maryland	X			X	X	X
Massachusetts	X	X		X	X	X
Michigan	X				X	X
Minnesota	X	X	X	X	X	X
Mississippi	X	X			X	X
Missouri	X				X	X
Montana	X	X			X	
Nebraska	X	X			X	X
Nevada	X			X	X	X
New Hampshire	X	X		X	X	
New Jersey	X	X			X	X
New Mexico	X				X	X
New York					X	
North Carolina	X	X			X	X
North Dakota	X	X			X	X
Ohio	X	X			X	X
Oklahoma	X	X			X	X
Oregon	X	X			X	X
Pennsylvania	X				X	X
Rhode Island	X	X		X	X	X
South Carolina	X	X			X	X
South Dakota	X	X			X	X
Tennessee	X	X			X	X
Texas	X				X	X
Utah	X	X			X	X
Vermont	X	X		X	X	X
Virginia	X	X			X	X
Washington	X	X			X	X
West Virginia	X			X	X	X
Wisconsin	X	X	X		X	X
Wyoming	X			X	X	
Total	50	30	2	15	51	46

State	Language	Pregnancy ¹	Intellectual and Developmental Disability	Employment	Sexual Orientation, Gender Identity ²	Income	Crowded Housing	Insurance Status	Residence Type ³	Housing Status	Comorbidity
Alabama											X
Alaska											
Arizona									X		X
Arkansas									X		X
California					X	X	X	X			
Colorado									X		
Connecticut									X		
DC											
Delaware											X
Florida									X		
Georgia		X							X		X
Hawaii											
Idaho											
Illinois									X		
Indiana									X		
Iowa				X					X		X
Kansas											
Kentucky									X		
Louisiana											X
Maine											
Maryland									X		
Massachusetts									X		X
Michigan									X		
Minnesota	X								X	X	
Mississippi									X		X
Missouri											
Montana									X		X
Nebraska											
Nevada											
New Hampshire											
New Jersey									X		
New Mexico									X		X
New York									X		X
North Carolina									X		X
North Dakota									X		
Ohio									X		
Oklahoma									X		X
Oregon			X						X		X
Pennsylvania					X				X		X
Rhode Island					X				X		
South Carolina									X		X
South Dakota									X		
Tennessee		X							X		
Texas									X		
Utah									X		X
Vermont		X	X						X		X
Virginia									X		
Washington	X			X					X		
West Virginia									X		
Wisconsin									X		
Wyoming											X
Total	2	3	2	2	3	1	1	1	36	1	20

1 Data is not published regularly.

2 Some states collected, but did not report this data.

3 Data is limited and reflects cases or outbreaks in long-term care facilities only.

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