

# Disaggregation of Public Health Data by Race & Ethnicity

A Legal Handbook

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## Disclaimers

The Network for Public Health Law provides information and technical assistance on issues related to public health law and policy. This handbook should not be considered legal advice. For legal advice, please contact your attorney. The experts consulted for this project are not responsible for the content of this handbook.

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# Executive Summary



# This handbook addresses the role of law in collecting and disseminating public health data disaggregated by race and ethnicity for public health practitioners and attorneys across state,

Tribal, and local governments. It is intended to assist practitioners and attorneys with framing and navigating the various legal and non-legal issues around disaggregated public health data.<sup>1</sup> Data disaggregation is the breakdown and categorization of large sets of data by certain data elements, such as race and ethnicity.

Detailed race and ethnicity data in public health is needed to adequately identify, assess, and address health inequities and structural racism in ways that engage all branches and levels of government, community members, and stakeholders. The COVID-19 pandemic has highlighted inequities in infection rates, health outcomes, and vaccination rates among racial and ethnic groups.<sup>2</sup> As such, the COVID-19 pandemic has reaffirmed the need for public health data disaggregated by race and ethnicity (hereafter “disaggregated data” or “data disaggregation”) to advance health equity.

Research has shown that states’ collection of non-white racial and ethnic group data has long been incomplete and unreliable.<sup>3</sup> To be sure, collecting and accessing disaggregated data alone will not end inequitable health outcomes, but it is an essential first step. With accurate and complete public health data, policymakers can be better equipped to interpret and use data to dismantle the legal, social, political, and economic systems that create inequities in the first place.

This handbook is organized into 5 sections. Section 1 describes the urgent need for disaggregated data. Section 2 describes the legal authority and process for public health data surveillance and privacy of public health data. Section 3 discusses the role of law in facilitating the collection of race and ethnicity in public health data sets. Section 4 explores legal considerations for disseminating disaggregated data. Section 5 describes considerations for intergovernmental data sharing. The handbook ends with a short conclusion and summary of recommendations.

The audience for this handbook includes practitioners and attorneys across state and local public health departments. While Tribal governments have the sovereign authority to conduct their own public health surveillance programs, Tribes have unique legal and policy considerations in conducting these programs which are not evaluated in this handbook. However, this

handbook identifies data disaggregation issues that affect Tribes and Indigenous communities and offers suggestions for state, Tribal, and local intergovernmental partnerships.

## Key Findings and Recommendations

One of our most important conclusions is that the law is generally not a barrier to public health departments collecting and disseminating disaggregated race and ethnicity data. Although sometimes cited as an impediment, the law is more often a facilitator, such as when it requires or permits entities to report data that includes race and ethnicity to health departments. Likewise, the law facilitates dissemination of disaggregated data through freedom of information laws and de-identification methods.

**General Legal Authority.** State, Tribal, and local public health departments generally possess the legal authority to collect and disseminate population-level disaggregated data. The development of effective public health interventions that reduce health inequities depends on the availability of accurate, representative, and timely health and demographic data. While health departments across the country are committed to addressing racial and health equity, such data is inconsistently collected and disseminated for a variety of legal and non-legal reasons.

**Data Collection.** One of our key findings is that the law facilitates health departments' ability to collect race and ethnicity data. For example, the Health Insurance Portability and Accountability Act (HIPAA), often a perceived barrier, allows disclosure of protected health information (PHI) to public health authorities for public health purposes. Likewise, state, Tribal, and local health departments possess the legal authority to collect disease and other information, including race and ethnicity data.

**Data Collection Barriers.** The barriers to collecting race and ethnicity data are generally non-legal, meaning that the law does not prevent data collection. Rather, we identified several non-legal barriers, including:

- Patient hesitance to provide their race and ethnicity at the point of collection;
- Data reporters not providing the data;
- Information system limitations;
- Insufficient guidance, requirements, or standards for data collection and coding; and
- Limited resources or staffing at the public health department.

The two largest barriers are the hesitancy of patients to disclose this information about themselves and the failure of providers to report it.

**Opportunities to Address Data Collection Barriers.** Nonetheless, there are opportunities for using the law to address the non-legal barriers to public health data collection. Among other things, we recommend that state health departments, utilizing existing legal authority, take steps to collect more complete race and ethnicity data across public health programs. We also recommend that states explore whether to explicitly mandate reporting of race and ethnicity data and whether to adopt or utilize penalties for failure to report such data.

At the federal level, we find that the federal government can do more to encourage data reporting to health departments and tie financial incentives to such reporting. We recommend that the Office of Management and Budget (OMB) expand its race and ethnicity categories in federal data collection (and we acknowledge that such a review is currently underway). Additionally, we recommend that Congress consider codifying requirements and providing sustainable funding for creating and maintaining a modern, robust, and interoperable governmental public health data infrastructure that includes key demographics such as race and ethnicity.

**Dissemination of Disaggregated Data.** Regarding public dissemination of disaggregated data, we note a central legal tension between: (1) the public's right to access public data; and (2) the individual's right to privacy. Importantly, we also find that law is a facilitator of public dissemination of disaggregated data. At the same time, such disaggregation has the potential to increase the risk of re-identification. We determine that these risks can and should be managed, particularly with the assistance of statisticians trained in disclosure risk assessment and limitation methods.

Traditionally, race and ethnicity are not considered direct identifiers, although we note they can increase the risk of re-identification for individuals represented in a dataset. Such risks can be realized through linkage with other demographic characteristics, which are often found in public datasets. We find that these risks can be offset by using statistical disclosure risk assessments and control methods.

**Improving Dissemination of Disaggregated Data.** Opportunities also exist to enhance dissemination of disaggregated data. We recommend that local and state health departments invest resources to more readily and easily render data de-identified, and thereby promote dissemination of disaggregated data. For example, state and local health departments can recruit individuals familiar with generally accepted statistical and scientific methods for rendering information not individually identifiable, and train staff on HIPAA's Safe Harbor method of de-identification. We also recommend that the federal government provide additional support to state and local health departments through training and other methods to support and promote the dissemination of disaggregated data. Finally, we recommend that state and local health departments develop and implement strong policies around data suppression and open data release, as well as unambiguous criteria to evaluate data requests.

**Intergovernmental Data Sharing.** In concluding the handbook, we address the need for intergovernmental data sharing among federal, state, Tribal, and local agencies to better assess and address equity, inclusion, and the social determinants of health. The type of data shared across government entities can vary substantially and can include fully identifiable, de-identified, aggregated, or disaggregated data, or a combination thereof.

Accordingly, we recommend that health departments consider master data sharing agreements with intergovernmental partners that permit ongoing data sharing through the addition of data-exchange-specific task orders or appendices. We also recommend that local health departments consider exercising their public health authority to require certain data exchanges, such as through an ordinance or executive order. Local health departments may also explore participating in health or other information exchanges and incentivizing partners to participate in such information exchanges.

Like all governments, Tribes have the authority and responsibility to promote the health and welfare of their community members. Tribal governments also engage in intergovernmental collaboration and coordination to promote public health in their communities and among their neighbors. States frequently deny Tribal access to data that they otherwise would make available to other state and local health departments.<sup>4</sup> Likewise, we recommend that state law and policy that hinders Tribal data sharing needs to be removed or amended so that Tribes have at least as much access as other public health authorities.

We also recommend that state and local governments consider how collecting and sharing identifiable or disaggregated data can affect Tribal sovereignty, including data sovereignty. States should negotiate data sharing agreements with Tribal nations that address how the state will collect, distribute, and use American Indian and Tribal data. To avoid undermining Tribal public health authority and public health programming in Indian Country, we recommend that states engage in rigorous consultation with Tribes and enter into intergovernmental data sharing agreements.

## Conclusion

The legal landscape of public health data collection, dissemination, and sharing is nuanced and complicated. As outlined above, and throughout this handbook, a variety of considerations and opportunities exist to improve both collecting and disseminating race and ethnicity data in public health to inform and address inequities. Our hope is that this handbook demystifies the current legal landscape and identifies actionable opportunities to use the law to improve public health data collection and dissemination.





# Introduction



# If communities are not counted, inequities cannot be identified, and community needs cannot be met. This handbook addresses the role of law in the disaggregation of public health data by

**race** and **ethnicity**. **Data disaggregation** is the breakdown and categorization of large sets of data by certain data elements.<sup>5</sup> Data disaggregated by race and ethnicity is necessary to advance health equity (hereafter "disaggregated data" or "data disaggregation").

For purposes of this handbook, we define race as a socially constructed system of categorizing humans largely based on observable physical features (phenotypes), such as skin color, and on ancestry. There is no scientific or discernable distinction between racial categories.<sup>6</sup> We define ethnicity as a social construct that divides people into smaller social groups based on characteristics such as a shared sense of group membership, values, behavioral patterns, language, political and economic interests, history, and ancestral geographic base.<sup>7</sup> We acknowledge that definitions may vary in substance and over time and that our expertise in this handbook lies in how the law treats race and ethnicity data collection and dissemination in public health.

A key conclusion of this report is that the law is not a barrier to public health departments collecting race and ethnicity data (see **Section 3**). Although sometimes cited as an impediment, the law is more often a facilitator, such as when it requires or permits entities to report data that includes race and ethnicity to health departments.

More frequently, provider or patient hesitance, as well as technical, resource, and other non-legal issues are responsible for inconsistent reporting of race and ethnicity data. As noted in **Appendix 2**, other public health organizations have identified barriers to public health data disaggregation in the context of methodology and technology. It is imperative that states and the federal government address these non-legal barriers, and that providers and other data reporters work to collect and share race and ethnicity data with public health departments. **Section 3** offers several recommendations at the state and federal level to improve public health data collection.

Another key conclusion is that the law is a facilitator of public dissemination of disaggregated data – which plays an important role in revealing **health inequities**. However, particularly in the context of disaggregated data, failing to adequately protect the **privacy** of individuals has the potential to actually harm members of underserved subpopulations or Tribal nations

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Terms in **bold** are defined in the Glossary of Key Terms (**Appendix 1**).

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Used throughout the handbook:

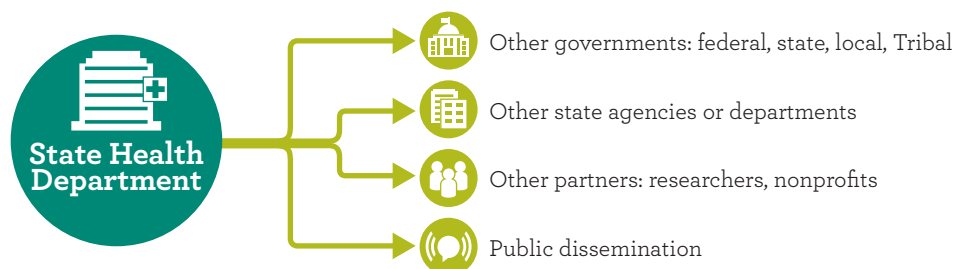
- ★ Recommendation
  - 🔍 Key finding
-

who may be at heightened risk of harm.<sup>8</sup> Dissemination of disaggregated data therefore requires state and local governments to balance public access to public data with the individual's right to privacy.

Data disaggregation has the potential to increase the risk of **re-identification** (see **Section 4**). Re-identification is the process of using data within a dataset, typically in combination with other, often publicly-available, data, to identify individuals who are the subject of the data. This handbook finds the added risk of potential re-identification can and should be controlled, particularly with the assistance of statisticians trained in disclosure risk assessment and limitation methods. **Section 4** offers several recommendations on how health departments can navigate the tension between public access and privacy.

In addition, state health departments regularly receive requests for data access from other state agencies, local health departments, Tribal governments, federal agencies, and other nonprofit and research partners (Figure 1). Law underpins the sharing of this data. **Section 5** considers how law impacts data sharing in these contexts and makes recommendations to improve data sharing.

**FIGURE 1: RACE AND ETHNICITY DATA SHARING BY STATE HEALTH DEPARTMENTS**



While Tribal governments have the sovereign authority to conduct their own **public health surveillance** programs, including the collection, dissemination, and sharing of disaggregated data, Tribal nations have unique legal and policy considerations in conducting these programs. These issues are outside the scope of this handbook. However, this handbook identifies data disaggregation issues that affect Tribes and Indigenous communities and offers suggestions for state, Tribal and local intergovernmental partnerships.

We also acknowledge that race and ethnicity are not the only data points relevant to assessing and addressing health inequities (other data points might include gender, sexual orientation and gender identity, rural or urban residence, socio-economic status, educational attainment, geography, housing status, and so on). Additionally, simply collecting race and ethnicity data (ideally self-identified) may not sufficiently capture how someone identifies nor how they are perceived when accessing health care and other services. These intersectional and multi-dimensional aspects of identity, while critically important, are not well-defined or addressed in law and are, therefore, outside the scope of this handbook.

## Organization and Methods

The audience for this handbook includes public health practitioners across state and local governments, including attorneys, epidemiologists, and program managers. The handbook is intended to assist these practitioners, who may not have extensive experience in the legal aspects of data collection and sharing, with framing and navigating the legal issues and dilemmas around collecting and disseminating disaggregated data.

This handbook is organized into 5 sections. **Section 1** describes the urgent need for disaggregated data. **Section 2** describes the legal authority and process for public health data surveillance and privacy of public health data. **Section 3** discusses the role of law in facilitating the collection of race and ethnicity in public health datasets. **Section 4** explores legal considerations for disseminating disaggregated data. Finally, **Section 5** describes considerations for data sharing with governmental and other partners and contains a series of practice recommendations.

To inform this handbook, the Network for Public Health Law (the Network) first reviewed the laws of ten states – California, Ohio, Michigan, Nebraska, New Jersey, New York, Nevada, North Carolina, Tennessee, and Texas. Specifically, we researched states’ legal authority to collect race and ethnicity data for disease surveillance, immunizations, and death records. This allowed us to examine how state laws differ and whether state law facilitates or hinders collecting race and ethnicity data. We also researched the overall legal landscape for disseminating disaggregated data and for privacy protections that may limit disseminating this data.

To conduct the analysis, we engaged co-authors who are experts in federal Indian law, Tribal law, data privacy, and data disaggregation. We also consulted various experts working with RWJF on data disaggregation, collection, and dissemination issues. These experts included staff at Croal Services Group, the Leadership Conference on Civil and Human Rights, and the UCLA Center for Health Policy and Research. We also consulted with experts at the American Indian Commission for Washington State, the Association of State and Territorial Health Officials, the Council of State and Territorial Epidemiologists, the Urban Indian Health Institute and epidemiologist Dr. Meghan Curry O’Connell.

CSTE helped arrange and conduct a discussion with members of its public health law and policy surveillance subcommittees, which include public health epidemiologists and legal counsel. Finally, the Network conducted an informal survey of its Privacy Officer Peer Group members to learn about state-level experiences collecting and disseminating race and ethnicity data. The Privacy Officer Peer Group, facilitated by the Network’s Mid-States Regional Office, brings together more than 80 privacy officers and legal counsel from state health departments across the country.



Section 1.

Disaggregated  
Data by Race  
and Ethnicity Is  
Needed to Further  
Health Equity

# The development and implementation of public health interventions that effectively reduce health inequities depends on the availability of accurate, representative, and timely health and

demographic data. Practitioners, policymakers, and the public need disaggregated data to measure the impact of diseases and interventions consistently, equitably, and reliably across all populations.<sup>9</sup> Essentially, disaggregated data can help illuminate and combat the health impacts of systemic racism and the unequal distribution of public health services.<sup>10</sup>

The COVID-19 pandemic presents a compelling recent example of this – expedient, life-saving public health information was urgently needed but often unavailable or delayed.<sup>11</sup> For example, an October 2021 study found race and ethnicity data was unavailable for almost 40 percent of people testing positive for COVID-19 or receiving a COVID-19 vaccine.<sup>12</sup> Other studies have found similar treatment disparities.<sup>13</sup> For instance, the National Patient-Centered Clinical Research Network found lower use of monoclonal antibody treatment among non-white patients with positive SARS-CoV-2 test results.<sup>14</sup> Ultimately, multiple analyses of the available data demonstrated that the pandemic disproportionately burdened Pacific Islander, Latino, Indigenous, and Black Americans. As a result, these groups experienced a higher incidence of COVID-19 infection and a death rate more than double that of Whites and Asian Americans generally.<sup>15</sup>

In contrast, the Centers for Disease Control and Prevention (CDC), found improved COVID-19 testing and vaccination reporting data from public health departments and other sources.<sup>16</sup> These reports include race and ethnicity for 74.3 percent of people with at least one dose administered,<sup>17</sup> thanks in part to federal efforts in the Coronavirus Aid, Relief, and Economic Security Act (CARES Act) and US Department of Health and Human Services (HHS) guidance.<sup>18</sup> Some of these improvements were restricted to COVID-19 data, and race and ethnicity data for other critical public health diseases remain highly incomplete or missing.

Nonetheless, the significant gaps in COVID-19 data collection reflect historical patterns.<sup>21</sup> Even as the COVID-19 pandemic has reaffirmed the need for disaggregated public health data to advance health equity, research demonstrates that incomplete and unreliable state health data collection regarding non-white racial and ethnic groups has been an issue *for decades*.<sup>22</sup> One study found that health disparities between whites of Western European descent and those of Middle Eastern or Eastern European descent are almost as large as those between white

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**Race** is a socially constructed system of categorizing humans largely based on observable physical features (phenotypes), such as skin color, and on ancestry. There is no scientific or discernable distinction between racial categories.<sup>19</sup>

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**Ethnicity** is a social construct that divides people into smaller social groups based on characteristics such as shared sense of group membership, values, behavioral patterns, language, political and economic interests, history, and ancestral geographical base.<sup>20</sup>

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and non-white individuals.<sup>23</sup> Another study even cautioned against relying on state-reported Medicare data given misclassification under racial beneficiary codes.<sup>24</sup>

Not surprisingly, numerous organizations, including the American Medical Association,<sup>25</sup> the American Public Health Association,<sup>26</sup> and the Robert Wood Johnson Foundation,<sup>27</sup> have called for data disaggregation as an important tool in addressing the role of racism in health inequities. However, public health surveillance systems in the United States have not been designed to collect and analyze race and ethnicity data systematically and across datasets.<sup>28</sup> The lack of data standards among registries and electronic data sets, interoperability across systems, and workforce capacity for data specialists have created a public health data system with infrastructure needs and hampered surveillance.<sup>29</sup> Fortunately, as discussed throughout this handbook, law and policy can support more complete collection, disaggregation, and dissemination of this data across the public health system and beyond. The availability of more complete and accurate race and ethnicity data will not only contribute to combating the health impacts of systemic racism and the unequal distribution of public health services – it will improve the nation’s public health system and beyond.

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Section 2

# The Law that Underpins Public Health Surveillance and Data Disaggregation

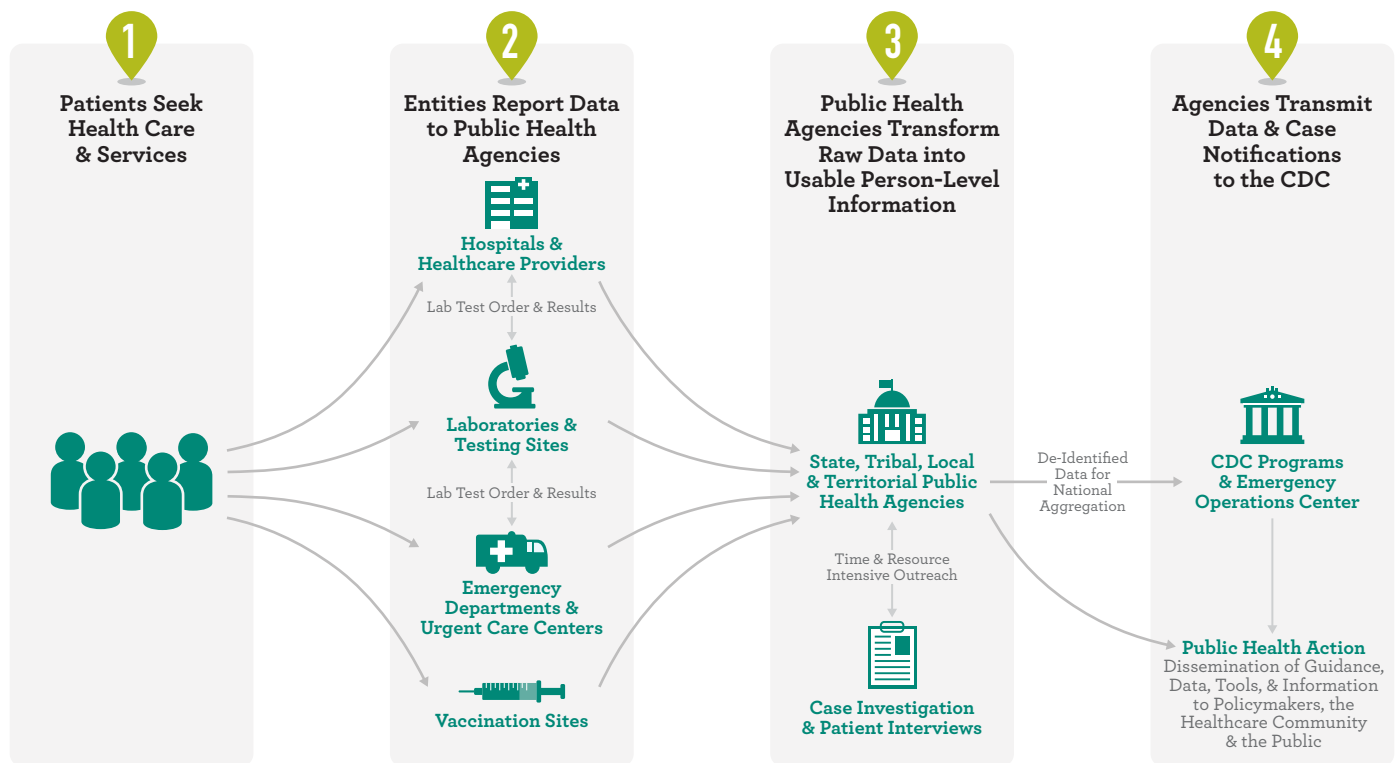


The law provides a broad framework for collecting, sharing, and disseminating public health data. This section provides a summary of these laws to provide a foundation for the more detailed discussion

of data collection and dissemination of disaggregated data in **Sections 3** and **4**. First, this Section discusses the legal authority for public health data collection. It then offers a brief overview of the privacy landscape.

States, Tribes, and local governments have the primary responsibility and authority to protect the public's health, along with the authority to collect data, including race and ethnicity data. Sources of public health data include disease and health event reports produced in clinical settings, vital records, immunization registries, surveys, the U.S. Census, and case investigations, among other sources (**Figure 2**). Reporting to health departments occurs in a variety of ways. For some disease surveillance data, health care providers, hospitals, laboratories, and other entities are required under state law to

**FIGURE 2: DATA FLOW FROM HEALTHCARE TO PUBLIC HEALTH AGENCIES**



Data flow graphic provided courtesy of the Council of State and Territorial Epidemiologists & Panzer Creative, 2022.

provide data on reportable conditions.<sup>30</sup> Vaccine administration data is submitted to immunization information systems by providers administering vaccines, including physicians, hospitals, pharmacies, and mass vaccination sites (**Figure 2**).<sup>31</sup>

States, Tribes, and local governments have the primary responsibility and authority to protect the public's health.

## Legal Authority for Public Health Data Collection

### State and Local Authority

Every state requires certain diseases, conditions, and health events to be reported to state health departments, and further outline what information or data elements are collected. Collecting this data has been upheld as a constitutional exercise of public health authority.<sup>32</sup> Federal policy can also incentivize states to establish these requirements. But even when required to report data, some data reporters provide incomplete data<sup>33</sup> to health departments.<sup>34</sup>

State law generally imposes an affirmative duty on health care providers to report diseases of interest,<sup>35</sup> and can be utilized to encourage consistent reporting of race and ethnicity to public health departments. Race and ethnicity are almost always required data fields, whether by law, rule, or policy (see **Figure 3**). For example, California's Department of Health, by rule, mandates that race and ethnicity be included in disease reports.<sup>36</sup> North Carolina requires all of the elements required by the federal standards established by the US Department of Health and Human Services (HHS), as discussed further below.<sup>37</sup> New Jersey<sup>38</sup> and Michigan<sup>39</sup> by rule require the inclusion of race and ethnicity, but do not specify whether the federal standards must be used. Other states include race and ethnicity in their reporting forms and rely on their general authority to dictate the form of a report.<sup>40</sup>

**FIGURE 3: UNDERSTANDING STATUTES, RULES, & POLICIES**

	Statute*	Rule**	Policy
Who	Adopted by a legislative body (state legislature or U.S. Congress) and signed by the executive (governor or president)	Adopted by a state or federal agency acting within the bounds of its statutory authority after notice to the public and opportunity for public comment	Adopted by a state or federal agency, consistent with law or rule, without the requirement for public notice and comment
Effect	Legally binding	Often fills in details of legislation; legally binding once adopted	Explains an agency's interpretation of their rule or policy. May or may not bind the agency or regulated individuals; depends on the substance of the policy, the authority in which it is issued, and the jurisdiction

\* Also known as law, Act, enacted legislation, legislation

\*\* Also known as regulation

The absence of statutory or regulatory language expressly authorizing or requiring collection of data, including race and ethnicity data, may present a dilemma for health departments that prefer to collect data with clear legislative authority. Absent express authority, health departments must rely on general public health authority to collect data. Such authority typically grants a state or local health department discretion to organize programs and interventions aimed at controlling disease and promoting the public's health. This broad and flexible authority allows the health department to address a wide array of public health issues.<sup>41</sup> A 2015 study of jurisdictions operating immunization registries for children found that 18.9% did so on the basis of general public health authority.<sup>42</sup> Of those jurisdictions operating adult immunization registries, the study found a full 25.5% of jurisdictions “relied on general public health statutes or regulations” rather than laws expressly authorizing the immunization registry.<sup>43</sup>

As a legal matter, health departments have adequate general authority to collect the data needed. Nevertheless, without express authority, health departments may not have the funding or the capacity to conduct adequate public health surveillance, especially if health care providers resist collecting and reporting the information.

### Federal Authority

Although state governments have the primary responsibility for public health surveillance, the federal government has numerous mechanisms for collecting or supporting the collection of health data. For example, the federal government funds and administers certain data collection efforts, such as the Behavioral Risk Factor Surveillance System. That system captures state-based data on US residents on a variety of health issues.<sup>44</sup> Under the federal government's taxing and spending power, the federal government may place conditions on the receipt of federal funds. For example, CDC grants may require grantee states to report certain test results or data elements as a condition of receiving federal funds.<sup>45</sup> CDC funding may also require states to use specific reporting systems and report specific data fields when sharing immunization data.<sup>46</sup> This, in turn, can induce the states to implement policies around data collection that the federal government could not otherwise mandate. Despite these requirements, CDC and HHS do not uniformly receive public health data from every state and territory.<sup>47</sup>

Perhaps more importantly, the federal government has established specific policies for collecting race and ethnicity data. The White House's Office of Management and Budget (OMB)<sup>48</sup> Directive No. 15, established in 1997 and revised in 2011,<sup>49</sup> creates five minimum categories of race (Table 1) and two minimum categories of ethnicity (Table 2) when collecting, analyzing or releasing data about race and/or ethnicity. This directive applies to the federal government and generally represents the baseline standard for race and ethnicity data collection for states.<sup>50</sup> What's more, the OMB standards are often applied in a variety of other data collection efforts administered

The OMB standards are often applied in a variety of other data collection efforts administered inside and outside the government, including household surveys, school registration forms, mortgage lending applications, and in medical and other research.

inside and outside the government, including household surveys, school registration forms, mortgage lending applications, and in medical and other research.<sup>51</sup>

**TABLE 1: OMB DIRECTIVE NO. 15 CATEGORIES OF RACE**

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

**TABLE 2: OMB DIRECTIVE NO. 15 CATEGORIES OF ETHNICITY**

Hispanic or Latino
Not Hispanic or Latino

Unfortunately, these guidelines and standards are not consistently applied. Despite the authority HHS appears to have to standardize race and ethnicity data reporting, for most activities it only requests that the OMB minimum standards be used (Tables 1 and 2). By contrast, when HHS-sponsored health surveys are performed, the more detailed 2011 HHS standards adopted as required by section 4302 of the Affordable Care Act must be used (Tables 3 and 4).<sup>52</sup> In addition, while HHS requests that states report public health data that includes race and ethnicity using at least the OMB minimum standards, states do not always or consistently report this information.

**TABLE 3: ETHNICITY CATEGORIES REQUIRED FOR ALL HHS-SPONSORED HEALTH SURVEYS**

No, not Hispanic or Latino/a, or Spanish origin
Yes, Mexican, Mexican American, Chicano/a
Yes, Puerto Rican
Yes, Cuban
Yes, another Hispanic, Latino/a or Spanish origin

**TABLE 4: RACIAL CATEGORIES REQUIRED FOR ALL HHS-SPONSORED HEALTH SURVEY**

American Indian or Alaska Native	Asian Indian
Chinese	Filipino
Japanese	Korean
Vietnamese	Other Asian
Black or African American	Native Hawaiian
Guamanian or Chamorro	Samoan
Other Pacific Islander	White

As noted above, OMB Directive No. 15 sets out minimum categories for race and ethnicity for federal agencies' data collection activities. But state and local health departments are not required to use the OMB categories when collecting race and ethnicity data, although federal policy may require reporting in a specific format as a condition of funding.<sup>53</sup> States may use the OMB categories or may consider adopting racial and ethnicity categories that best reflect their communities, although these additional categories would likely be aggregated into the standard categories when shared with the federal government.<sup>54</sup> A consideration in deviating from OMB's categories is whether the dataset collected will facilitate required reporting to CDC or HHS, which generally require, at a minimum, use of, or compatibility with, OMB's categories.

The OMB categories are not without nuances, gaps, and contentions.<sup>55</sup> The OMB standards have been criticized for failing to “reflect the increasing diversity” of the U.S.<sup>56</sup> For example, sociologist Dr. Neda Maghbouleh has studied the limitations of categorizing Middle Eastern and North African Americans as white, finding the hypervisibility of Middle Easterners in the US results in disparate treatment from other white individuals.<sup>57</sup> As another example, research has shown that aggregating distinct communities of Asian Americans into one category fails to capture the diversity within the category and the substantial health disparities depending on subcategories.<sup>58</sup>

Another persistent issue is the challenge of capturing complete information for individuals who identify as more than one race or ethnicity, or “multiracial,” particularly when third-parties are selecting categories for individuals. More nuanced identity criteria, through self-identification, such as skin tone and linguistics, are not captured in the OMB categories.<sup>59</sup> Additionally, perceived racial and ethnic identity may vary from an individual's actual identification and can lead to racial misclassifications.<sup>60</sup>

A particularly unique issue relates to the intersection of race and Tribal citizenship. Although American Indians and Alaska Natives are considered a racial/ethnic group, Tribal membership is a political classification established by Tribal citizenship law and policy<sup>61</sup> and recognized under federal law.<sup>62</sup> These distinctions are nuanced, and identification preferences vary. For example, not all American Indians and Alaska Natives are enrolled citizens of a Tribe.<sup>63</sup> In addition, disaggregated public health data that distinguishes the race and ethnicity classifications of American Indians and Alaska Natives, very rarely identifies the political classification of Tribal citizenship.<sup>64</sup> Often, racial/ethnic identification as an American Indian or Alaska Native is done by self-identification, like in US Census data.<sup>65</sup> Additionally, an individual may be a Tribal citizen without identifying as American Indian as a racial classification.<sup>66</sup>

Data quality issues persist with public health data regarding American Indians and Alaska Natives. Racial misclassification, biracial classification, and small sample sizes are pervasive data collection issues.<sup>67</sup> Public health data does not capture the nuances with Tribal citizens living on, near, and far

from Tribal lands.<sup>68</sup> American Indians and Alaska Natives also receive care across Tribal, federal, and state providers, making data collection systems particularly complex.<sup>69</sup>

Finally, racial and ethnic categorizations do not capture **intersectionalities** in identity.<sup>70</sup> Gender, sexual orientation, educational attainment, and other identities, characteristics, and experiences can be associated with health inequities on their own. In combination, intersectional identities can be associated with unique health inequities or exacerbate existing ones.<sup>71</sup>

Overly broad or inaccurate categorization of race and ethnicity can influence health outcomes and ignore many leading drivers of health inequities. Importantly, OMB's broad categorizations create a floor, not a ceiling, for public health surveillance. In June 2022, the White House announced that it would be undergoing a formal review and revision of the OMB race and ethnicity standards.<sup>72</sup> In the meantime, as described in **Section 3**, states have the authority to capture more nuanced information to advance their public health goals.

### Tribal Authority

Tribes are sovereign governments with a nation-to-nation relationship with the United States and government-to-government relationship with states, locals, and other Tribes.<sup>73</sup> There are 574 federally recognized Tribes.<sup>74</sup> Tribal inherent sovereignty includes the authority and responsibility of any nation-states,<sup>75</sup> which includes a duty to protect and promote the public's health.<sup>76</sup> Although European colonization and the founding of the United States has disrupted the exercise of Tribal jurisdiction,<sup>77</sup> in areas of public health, Tribes retain their authority at the exclusion of state governments.<sup>78</sup>

Tribal inherent public health authority includes, but is not limited to, communicable disease prevention and control through isolation and quarantine, tobacco cessation and environmental health programming, conducting case investigations, and contact tracing, dispensing and distributing vaccines, and public health surveillance.<sup>79,80</sup> Many Tribes engage in systematic public health data collection<sup>81</sup> or work with partners, such as Tribal Epidemiology Centers (TECs),<sup>82</sup> to conduct surveillance work. Tribes also regularly enter into data sharing agreements to facilitate data access with other governments (see **Section 5**).

## The Privacy Landscape

### State and Tribal Privacy Laws

The privacy landscape in which today's health department finds itself is an ever-growing body of privacy laws. The constitutions of Alaska, Arizona, California, Florida, Hawaii, Illinois, Louisiana, Montana, New Hampshire, South Carolina, and Washington include an express right to privacy, although the specific rights vary in scope.<sup>83</sup> In some states, the protection is similar to the Fourth Amendment's protection against unreasonable

Overly broad or inaccurate categorization of race and ethnicity can influence health outcomes and ignore many leading drivers of health inequities. Importantly, OMB's broad categorizations create a floor, not a ceiling, for public health surveillance.

searches and seizures<sup>84</sup> and protects against unreasonable intrusions on privacy.<sup>85</sup> In Montana and Hawaii, the state can only collect, use, or disclose personal information to advance a substantial government interest.<sup>86</sup>

A common element of privacy laws is to require consent from the individual or the individual's authorized personal representative prior to using or disclosing the individual's information.<sup>87</sup> In a reflection of the need to balance privacy with the public good, privacy laws generally include different exceptions to the required consent or authorization for research,<sup>88</sup> judicial proceedings,<sup>89</sup> mandatory reporting of child abuse and neglect,<sup>90</sup> and public health.<sup>91</sup>

By statute or rule, every state regulates how the information in disease reports can be used and with whom it can be shared. No state prohibits its health department from disseminating **de-identified data** amassed from reported diseases.<sup>92</sup> Yet the standards for determining when public health data is anonymous enough to be disseminated vary by state and are rarely harmonized with the Health Insurance Portability and Accountability Act (HIPAA) de-identification standard (see **Section 4**). For example, disclosure in some states usually occurs in a way that “no person can be identified,”<sup>93</sup> while in others disclosures must occur “without linking the information disclosed to the individual.”<sup>94</sup> In contrast, a few jurisdictions allow communicable disease information to be released to further public health even if the release discloses an individual's identity.<sup>95</sup> For instance, New Jersey expressly allows data to be released for statistical and epidemiologic purposes.<sup>96</sup> New Jersey law also specifically requires disclosure of demographic data related to COVID-19 to the public that includes race and ethnicity, even at the county and municipal level.<sup>97</sup> Additionally, five states currently have comprehensive consumer privacy protection laws: California; Colorado; Connecticut; Virginia; and Utah.<sup>98</sup> Although not specific to health data, these privacy protection laws are often broad enough to cover certain types of health data.<sup>99,100</sup>

Many Tribes have health privacy laws or research codes that can implicate state and local governmental public health surveillance efforts. While the jurisdictional landscape on the application of Tribal law and policy is complex, state and local governments recognize and respect Tribal sovereignty through Tribal consultation and data sharing agreements, discussed in more detail in **Section 5**.

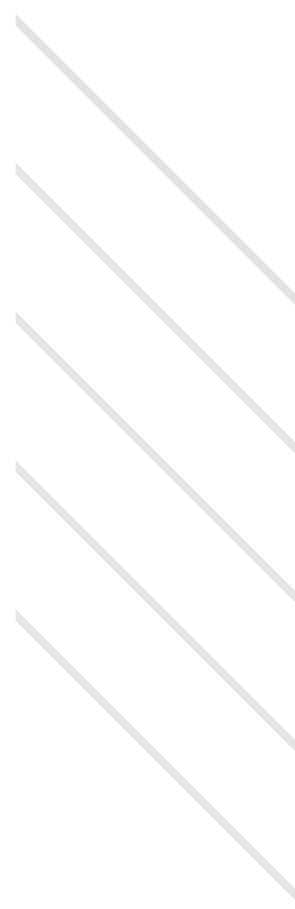
## HIPAA

A variety of federal laws govern the privacy of health-related data including: Medicaid;<sup>101</sup> Family Educational Rights and Privacy Act (FERPA);<sup>102</sup> 42 CFR Part 2;<sup>103</sup> Assurances of Confidentiality;<sup>104</sup> Privacy Act;<sup>105</sup> and Women, Infants, & Children (WIC) **confidentiality**.<sup>106</sup> This handbook focuses primarily on the HIPAA.<sup>107</sup> Since 2003, HIPAA has provided a legal framework that accentuates confidentiality of health information. Because HIPAA is referenced in several sections within this handbook, we provide a basic overview of HIPAA in the context of data collection and dissemination.

The standards for determining when public health data is anonymous enough to be disseminated vary by state and are rarely harmonized with the HIPAA de-identification standard.

HIPAA covers three types of entities – health plans, health care clearinghouses, and health care providers – who transmit protected health information (PHI – the identifiable health data HIPAA protects)<sup>108</sup> in electronic form regarding a HIPAA-covered transaction. Such transactions include health care claims or equivalent encounter information, health care payment and remittance advice, coordination of benefits, etc.<sup>109</sup> HIPAA’s rules also apply to business associates, broadly defined as persons or entities handling PHI on behalf of the covered entity.

Covered entities are subject to both the HIPAA Privacy Rule and HIPAA Security Rule.<sup>110</sup> These covered entities must safeguard PHI against improper use or disclosure.<sup>111</sup> The HIPAA Privacy Rule generally requires a covered entity to obtain written authorization from the individual prior to use or disclosure of the individual’s PHI. However, the Rule permits uses and disclosures of PHI absent written authorization in several circumstances, including: where required by law; for health care treatment, payment, or operations; to a health oversight agency; and to a public health authority authorized to receive the information. Finally, a covered entity that is also a public health authority is permitted to use PHI in all instances in which it would be permitted to disclose PHI to a public health authority.<sup>112</sup>





# Data Collection and Privacy

## Immunization Reporting

Not all jurisdictions require reporting of vaccination data to the health department or immunization registry. Even when states mandate reporting of vaccinations to the health department, the mandate may not apply to all vaccinations. Many immunization registries were created to track childhood, and not adult, immunizations.

Our review of 10 states did not find consistent mandates for collecting and reporting race and ethnicity in immunization data. For example, California requires that gender be reported with immunization information but does not specify the same for race and ethnicity data.<sup>113</sup> Indeed, race and ethnicity in vaccination data is often lacking. Regarding COVID-19 vaccination data, 91% of jurisdictions indicated there were barriers to the collection of complete race and ethnicity data.<sup>114</sup>

Like all registries, immunization registries established by state law have provisions that restrict the use and disclosure of the records and information contained within the registry. For example, New York's statewide immunization tracking system makes the information in its immunization registry, as well as a separate New York City registry,<sup>115</sup> "confidential except as necessary to carry out" the registry's specified purposes.<sup>116</sup> Proper uses of de-identified information include epidemiological studies and disease control.<sup>117</sup> Thus, in New York, immunization data can be released to researchers or the public for communicating the state's response to a particular threat, or publicly disseminated as part of the state's epidemic response.

## Death Records

There are 57 registrars of vital statistics in the United States – one for every state and territory, and one for the cities of New York and Washington, DC. Each registrar requires deaths to be reported electronically and uses a form modeled on the US Standard Certificate of Death (model form).<sup>118</sup> The legislatures of Nebraska, Nevada, and Ohio have directed their states' registrars to use the model form.<sup>119</sup> The laws of the other states the Network for Public Health Law reviewed allowed their registrars to dictate the form and manner of death reporting.<sup>120</sup> Whether specifically directed to do so by its legislature or vested with the discretion to choose how deaths are reported, all state registrars are collecting the data specified on the model form. The model form goes further than OMB's Directive No. 15, discussed above, and includes additional race and ethnicity categories.<sup>121</sup>

While the actual restrictions differ, there are statutes or rules for every Registrar of Vital Statistics governing the release of death certificates and information contained in death certificates.<sup>122</sup> Although a decedent's right of privacy may be diminished, death certificates reveal information about cause of death and about living persons connected to the decedent. State laws, however, generally allow the release of de-identified death data to researchers.<sup>123</sup> They also allow death statistics to be shared with other agencies that need them for official purposes.<sup>124</sup>



Section 3.

Current Law  
Permits the  
Collection of Race  
and Ethnicity  
Data while  
Opportunities  
Exist to go Further

The law allows state and local public health departments to collect race and ethnicity data. Despite some misperceptions or conservative interpretations, we consistently found in our

research, and in consultations with experts to inform this handbook, that the law does not impede health departments from collecting this data.<sup>125</sup>

For example, in a recent Council of State and Territorial Epidemiologists (CSTE) report, only 5% of health departments identified the law as a barrier to collecting race and ethnicity data.<sup>126</sup> Indeed, the main barriers to consistently collecting these data – patient hesitance to disclose, provider non-reporting, and technological issues – are non-legal in nature.<sup>127</sup> The law, however, can facilitate more consistent and complete collection of race and ethnicity data. This section dispels misperceptions around Health Insurance Portability and Accountability Act (HIPAA) and provides several examples of current laws that facilitate collecting disaggregated data. In addition, this section identifies opportunities where law can address barriers to data collection, such as incentivizing providers to collect and report race and ethnicity data.

## Current Law Permits the Collection of Race and Ethnicity Data

Federal, state, and local law allow health departments to collect race and ethnicity data. HIPAA permits public health data collection, despite some perceptions to the contrary. In addition, the Office of the National Coordinator's (ONC) information blocking rule supports public health data collection. Some states have passed laws to require collection and reporting of race and ethnicity data that goes far beyond the Office of Management and Budget's (OMB) limited categories. Finally, state and local governments can use executive power to facilitate collecting disaggregated data. In fact, the COVID-19 pandemic resulted in the widespread use of executive authority to collect such data.

### HIPAA Allows Public Health Data Collection

HIPAA is not a barrier to public health data collection, and indeed permits disclosure of identifiable data to public health departments. HIPAA is sometimes cited as a legal reason that protected health information (PHI) may not be disclosed to a public health department. For example, HIPAA

The main barriers to consistently reporting race and ethnicity data – patient hesitance to disclose, provider non-reporting, and technological issues – are non-legal in nature.

may be cited as a reason why a mandated data reporter – such as a health care provider or laboratory – cannot disclose identifiable disease-related information to a health department. This is inaccurate.

As discussed in **Section 2** above, HIPAA generally requires an individual’s written authorization to share their PHI.<sup>128</sup> However, HIPAA contains a specific exception to its authorization requirement that allows covered entities to disclose PHI to public health authorities for public health purposes.<sup>129</sup> Public health authorities include federal, state, local, territorial, and Tribal government agencies that are responsible for public health as part of their official mandate.<sup>130</sup> It is important to note that HIPAA’s public health exception allows, but does not require, uses and disclosures of PHI for public health purposes.<sup>131</sup>

HIPAA’s public health exception limits disclosure of PHI to the “minimum necessary” for the intended public health purpose. In determining compliance with the minimum necessary rule,<sup>132</sup> HIPAA covered entities may rely on the public health authority’s representation that the information requested is the minimum necessary for public health purposes.<sup>133</sup> This means that a health department’s determination that disease or other public health reporting must include race and ethnicity data is sufficient to satisfy HIPAA’s minimum necessary rule.

In many cases, reporting data to health departments is mandated by law. Where reporting to a health department is required by another law or regulation, HIPAA’s “as required by law” exception would apply.<sup>134</sup> The minimum necessary rule does not apply to disclosures of PHI that are required by law.<sup>135</sup>

**Q** Thus, HIPAA is simply not a legal barrier to public health data collection, including race and ethnicity data.<sup>136</sup> HIPAA’s public health exception allows the use or disclosure of PHI to public health authorities. Health departments should educate providers and other data reporters on this misperception when it arises.<sup>137</sup>

**HIPAA’s public health exception allows, but does not require, uses and disclosures of PHI for public health purposes.**

### **Federal Information Blocking Rule Supports Public Health Data Collection**

The 21st Century Cures Act, among other things, sought to discourage what is known as “information blocking.”<sup>138</sup> The law defines information blocking as a practice that is likely to interfere with, prevent, or materially discourage access, exchange, or use of electronic health information. To violate the law, the person or entity engaging in the practice must know or should know that the practice is likely to discourage access, exchange, or use of electronic health information.<sup>139</sup> The act directed the Secretary of HHS to identify reasonable and necessary activities that do not constitute information blocking.<sup>140</sup>

In 2020, the Office of the National Coordinator (ONC) – the federal agency tasked with information blocking rulemaking – issued a final rule.<sup>141</sup> The rule applies to health care providers, certified health information technology

(IT) developers, and health information exchanges and networks.<sup>142</sup> The rule provides a number of exceptions (essentially safe harbors) where a covered entity will not be engaged in information blocking.<sup>143</sup>

The information blocking rule is intended to counter the overly conservative approach to data sharing and HIPAA compliance. Importantly, ONC has issued guidance that a healthcare provider who fails to report data electronically to a public health agency as required or authorized by law may be engaged in impermissible information blocking.<sup>144</sup> **Thus, a public health department may point to the information blocking rule and ONC's guidance to encourage reporting of identifiable health information, including race and ethnicity, needed for public health purposes. A health department may also point out or even utilize the law's enforcement mechanism.**<sup>145</sup>

## Use of State Law and Executive Powers to Aid Public Health's Collection of Race and Ethnicity Data

State law, as well as executive action, can be used to collect race and ethnicity data across government programs and the healthcare industry. Some states, such as Oregon and Washington, have passed legislation to collect data that reflects the diversity of their populations. During the COVID-19 pandemic, states and local governments used executive authority to require race and ethnicity data collection and reporting. This section highlights a few examples of states and local governments using the law to collect more robust race and ethnicity data.

### State Laws that Facilitate Robust Race and Ethnicity Data Collection

Oregon is an example of a state that enacted legislation requiring collection and reporting of race and ethnicity data that goes far beyond OMB's categories (discussed in **Section 2**). In its 2012 State of Equity Report, the Oregon Department of Human Services (ODHS) and the Oregon Health Authority (OHA) identified a need for more robust race and ethnicity data.<sup>146</sup> In 2013, the state legislature passed the Race, Ethnicity, Language, and Disability (REALD) data collection law, which required the two departments to develop data collection standards with input from community stakeholders facilitated by Oregon's Office of Equity and Inclusion (OEI). The legislation also required that all ODHS and OHA programs collect data biannually and allow residents to select more than one race.<sup>147</sup> ODHS, OHA, and OEI developed race and ethnicity categories to reflect Oregon's population, which include 39 different categories (in contrast to OMB's 7).<sup>148</sup> Questions must be asked in an open-ended format.<sup>149</sup> In addition, the agencies developed a number of resources aimed at educating providers and the public regarding the importance of race, ethnicity, and other demographics to identify and equitably serve the needs of Oregon's communities.<sup>150</sup> In 2020, the state passed a law requiring health care providers to collect REALD information at all health care encounters related to COVID-19 and to share this information with OHA.<sup>151</sup>

Washington is an example of a state that has utilized its existing authority to require more complete reporting of race and ethnicity data. The Washington Department of Public Health recently passed a regulation, effective January 1, 2023, that requires health care providers and facilities to report race, ethnicity, and preferred language when ordering a laboratory test for a reportable condition or submitting a case report. While ethnicity focuses simply on Hispanic, Latino/a/x or non-Hispanic, Latino/a/x, the regulation contains 71 racial categories and requires that patients be allowed to self-identify. Providers must report each race identified.<sup>152</sup>

Washington is an example of a state that has utilized its existing authority to require more complete reporting of race and ethnicity data.

### Use of Executive Authority to Collect Race and Ethnicity Data During COVID-19

Governors serve as a state's chief executive with responsibility for implementing state laws and overseeing the executive branch's operations.<sup>153</sup> Authority to issue executive orders comes from each state's constitution and statutes, as well as case law. Executive orders are used, among other things, to trigger emergency powers, create advisory and investigative commissions, and address management and administrative issues within the executive branch of state government.<sup>154</sup> In the first four months of the pandemic, every governor used this authority to issue more than 2,000 executive and state agency orders.<sup>155</sup> Some orders required increased data sharing with health departments. For example, Governor Ducey of Arizona required all licensed hospitals to report race and ethnicity data, among other demographics, for COVID-19 cases.<sup>156</sup>

During the COVID-19 pandemic, some states and local governments also used their public health authority to issue orders requiring race and ethnicity data to be collected and reported. For example, Colorado issued an order requiring COVID-19 vaccine providers to ask patients their race and ethnicity and provided the minimum race and ethnicity categories to be used.<sup>157</sup> At the local level, the city of Chicago's Commissioner of Health ordered all health care providers to report demographic data, including race and ethnicity, for any COVID-19 testing, vaccinations, clinical care, or treatment.<sup>158</sup> Similarly, the health officer for the city and county of San Francisco ordered that hospitals electronically share certain information on COVID-19 patients, including race and ethnicity data.<sup>159</sup>

Despite these examples, using executive authority has limitations. For instance, executive orders issued in response to an emergency are generally temporary. Executive orders may be amended or repealed without the same process required in law or rulemaking. The lack of process required may make executive orders more vulnerable to legal challenges. As a result, executive and public health orders are likely best used to bolster data collection efforts for a particular public health issue, such as COVID-19, where immediate action is needed. Legal efforts to improve data collection more generally are better resolved through law, rule, or policy implementing a law or rule (**Figure 3**).

## Opportunities to Utilize the Law to Address Data Collection Barriers

As described above, our research and consultations to inform this handbook did not find the law itself to be a barrier to collecting race and ethnicity

**Q** data. **Rather, it is non-legal barriers that complicate the public health data collection landscape, especially when it comes to race and ethnicity data.**

This subsection will explore the non-legal barriers to health departments' consistent collection of race and ethnicity data and discuss opportunities and strategies for the law to help address these barriers.

### The Non-Legal Barriers to Collection of Race and Ethnicity in Public Health Datasets

The barriers to collecting race and ethnicity data are generally non-legal, meaning that the law does not prevent data collection. In CSTE's recent report on collecting race and ethnicity data during the COVID-19 pandemic, state health departments identified several barriers, including:

- Patient hesitance to provide their race and ethnicity at the point of collection;
- Data reporters not providing the data;
- Information system limitations;
- Insufficient guidance, requirements, or standards for data collection and coding; and
- Limited resources or staffing at the public health department.<sup>160</sup>

**Q** **The two largest barriers health departments identified were the hesitancy of patients to disclose this information about themselves and the failure of providers to report it.**<sup>161</sup> These themes also came through in our expert consultations. Patient hesitance to disclose may be due in part to a history of mistrust in health systems and government reporting among some minority groups. Providers are not collecting or reporting data for a variety of reasons, including lack of training and education, as well as patient hesitance to disclose.<sup>162</sup>

The fact that data collection occurs largely outside of public health departments (i.e., at the provider, hospital, or laboratory level) is a challenge to the consistent collection of quality data.<sup>163</sup> Many provider electronic health record (EHR) systems and public health data systems do not allow for selection of more than one race or ethnicity, which significantly underrepresents multiracial and multiethnic identities. Selection of multiple races may result in an individual being reported as "other," which is not useful information for health departments. Additionally, not all race and ethnicity categories across EHRs and public health data systems are the same, meaning that data are not transmitted in a standardized fashion. An individual's identification with race and ethnicity categories may change over time or depend on how these categories are presented. All of this leads to inconsistent data and persistent data quality issues.<sup>164</sup>

Furthermore, technical issues and lack of interoperability among data systems is widespread<sup>165</sup> and are not limited to reporting entities. Silos within health departments, and government more generally, are common and result in different public health programs utilizing different data systems and, sometimes, different vendors.<sup>166</sup> Finally, governmental leadership and funding shape public health surveillance policy. Chronic underfunding of the public health infrastructure and technology exacerbates many of the barriers to consistent and quality public health reporting and data collection at a systems level.<sup>167</sup> **Without adequate funding and resources to comprehensively address these barriers, many health departments will continue to struggle to consistently collect quality race and ethnicity data across programs.**<sup>168</sup>

Without adequate funding and resources to comprehensively address these barriers, many health departments will continue to struggle to consistently collect quality race and ethnicity data across programs.

### Opportunities and Strategies for Using the Law to Address Data Collection Barriers

Opportunities exist to use the law to address the non-legal data collection barriers.<sup>169</sup> To be sure, what works in one jurisdiction may not work in another. Strategies, legal and otherwise, should be tailored to the unique needs of each jurisdiction while also supporting the ability to analyze data and identify trends at the local, state, and national levels. This work must also include community voices and stakeholders as co-contributors. With this in mind, this section identifies and discusses the following opportunities and strategies for the law to address data collection barriers:

- **Utilizing existing legal authority, states should take steps to collect more complete race and ethnicity data across public health programs.**
- **States can explore whether to explicitly mandate, through statute or administrative rule, reporting of race and ethnicity data.**
- **States can also explore whether to adopt penalty structures for failure to report such data.**
- **The federal government can do more to mandate provider<sup>170</sup> reporting to public health and tie financial incentives to such reporting.**
- **OMB can expand its race and ethnicity categories. Doing so would expand the floor of race and ethnicity categories that are used in data systems across the country.**
- **Congress should consider codifying requirements and providing sustainable funding – beyond what has been allocated to date – for creating and maintaining a modern, robust, and interoperable public health data infrastructure at all levels of government.**

### State Level Strategies to Facilitate Data Collection

As we have demonstrated, the law allows state and local health departments to collect race and ethnicity data,<sup>171</sup> and many already require this data to be reported. But health departments report that consistent collection of



race and ethnicity data is a challenge and that this data is not consistently received.<sup>172</sup> There are several strategies states can consider to address these deficiencies.

- ★ **First, states have the authority to expand their race and ethnicity categories beyond the CDC or HHS required categories to better reflect their jurisdiction’s communities.** State and local health departments can typically determine what data elements must be reported. **Utilizing existing legal authority, states should take steps to collect more complete race and ethnicity data across public health programs.**
- ★ **Second, health departments should consider adopting rules explicitly requiring reporting of race and ethnicity data that would include both an implementation and enforcement component.**<sup>173</sup> At the same time, health departments should be cautious of memorializing in law or rule specific race and ethnicity categories because it may limit flexibility to make future updates to better reflect a jurisdiction’s changing community.<sup>174</sup>
- ★ **Third, to the extent not already in place, health departments should adopt penalties for failure to report required information such as race and ethnicity.** As discussed above, compliance with public health reporting requirements is inconsistent for a variety of reasons.<sup>175</sup> In some states, such as New Jersey<sup>176</sup> and New York,<sup>177</sup> failing to report diseases in the form required by the health department can result in a provider or laboratory being fined. In addition, providers may be subject to disciplinary action against their professional license for failing to submit reports to a health department as provided in law.<sup>178</sup> While legal penalties may seldom be pursued,<sup>179</sup> the threat of penalty for failure to provide legally mandated data strengthens and reinforces public health outreach and education efforts and can be cited when a data reporter believes (often mistakenly) that identifiable data cannot be shared with a health department.<sup>180</sup>
- ★ **Fourth, state and local health departments should develop materials to educate providers on the applicable legal authority and the importance of collecting race and ethnicity data.** The lack of enforcement or education on reporting requirements may result in providers viewing them as suggested rather than required. Oregon and Washington state are examples of state-wide efforts to develop and implement inclusive race and ethnicity categories. In implementing its law, Oregon has developed robust provider and public education around the questions asked and the importance of collecting this data.<sup>181</sup>

### **Federal Strategies to Encourage and Facilitate Data Collection**

The federal government is in a position to provide nationwide leadership to improve the collection of race and ethnicity data through rulemaking, guidance, outreach, education, and so on – and to provide stakeholders with a clear vision and guidance, as well as technical and financial assistance.<sup>182</sup> The federal government’s role in data collection is essential because of

its role in administering health care programs (Medicare and Medicaid), providing care (Veterans' Administration and Indian Health Service), and administering a variety of public health data sets.<sup>183</sup>

★ **First, to assist state and local health departments with collecting race and ethnicity data, the federal government can do more to encourage or even require provider reporting to health departments.** Such strategies are already underway, although not universally applicable or required. For example, the Affordable Care Act requires that any federally conducted or supported health care or public health program, activity or survey collects and reports, *to the extent practicable*, certain demographic data, including race and ethnicity, to inform health disparities.<sup>184</sup> As described in **Section 2** above, such data is not universally collected or reported.<sup>185</sup>

In November 2021, Centers for Medicare and Medicaid Services (CMS) released a final rule making updates to its Medicare payment policies.<sup>186</sup> Among the changes adopted, CMS announced that providers treating Medicare patients would be required to share disease and immunization data with health departments. While not all public health data is included in the new policy, CMS will increase reimbursement for providers who report optional data to public health, such as syndromic surveillance.<sup>187</sup> In July 2022, CMS announced that it would be implementing software changes to enrollment and payment systems for Medicare Advantage and Medicare Prescription Drug programs to add race and ethnicity data fields. While there is room for improvement, the race and ethnicity data fields CMS will use go beyond OMB's required categories.<sup>188</sup>

★ In future updates, **CMS should expand the data it requires to be reported to public health departments and provide additional reporting incentives. Data reporting requirements or incentives should include race and ethnicity data.** CMS is also in a unique position to educate Medicare and Medicaid providers on the importance of collecting race and ethnicity data to achieve health equity and to assess the success of policy interventions. In addition to health care provider requirements and incentives, the federal government should also incentivize or require other data reporters – such as laboratories – to collect and report race and ethnicity data to health departments. Indeed, federal leadership – among HHS, ONC, and the federal government more generally – can likely help to resolve some of the race and ethnicity data collection barriers discussed above.<sup>189</sup>

★ Second, **another significant action the federal government can take to assist states in collecting more complete race and ethnicity data is to expand OMB's race and ethnicity categories.** As discussed in **Section 2** above, states are generally not required to utilize OMB's race and ethnicity categories. But since HHS requests reporting consistent with OMB standards, the result is that OMB's categories tend to be used as a baseline for collecting race and ethnicity data at the state and local levels. This issue may be resolved with OMB's formal review and revision of Directive No. 15. The review and revision was announced in June 2022, with a stated goal

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of completing revisions to OMB's race and ethnicity categories by summer 2024.<sup>190</sup> An expansion of OMB's categories would also be a step toward more unified race and ethnicity categories across the federal government.

★ Third, **Congress should consider codifying requirements and providing sustainable funding for creating and maintaining a modern, robust, and interoperable public health data infrastructure at all levels of government.**

Here too, efforts are already underway. A stated goal of the current data modernization initiative (DMI) is to have a foundation for public health data sharing at all levels, including “shared analysis capabilities to rapidly identify trends within and across jurisdictions, including race/ethnicity-specific trends and risk factors.”<sup>191</sup> A robust, interoperable public health data infrastructure that includes race and ethnicity data will help state and local health departments access and analyze such data to identify racial and health disparities, address and evaluate health equity interventions, and understand how people experience inequity and discrimination.

Funding to create and sustain such infrastructure is critical to public health's success. Indeed, the CDC readily acknowledges that modernization is not a one-time event.<sup>192</sup> In 2020, CDC received \$50 million dedicated to data modernization. This annual appropriation was increased to \$100 million in 2022.<sup>193</sup> The Coronavirus Aid, Relief, and Economic Security (CARES) Act provided CDC with \$500 million specifically for DMI.<sup>194</sup> Finally, the American Rescue Plan provided another \$300 million for DMI.<sup>195</sup> While significant, this funding is far short of current DMI funding estimates – ranging from \$7.84 billion over five years to \$36.7 billion over ten years<sup>196</sup> – and sustained funding is not guaranteed. However, sustainable funding is needed to ensure that the nation's public health data infrastructure bolsters and supports public health at all levels – today and for the foreseeable future.



Section 4.

Public  
Dissemination  
of Disaggregated  
Data: The  
Crossroads of  
Transparency  
and Privacy

Public dissemination of disaggregated data plays an important role in advancing health equity; however, without adequate controls to manage re-identification risks, dissemination has the

potential to actually harm members of underrepresented communities. This section focuses on the central legal tension in disseminating disaggregated data: (1) the public’s right to access public data; and (2) the individual’s right to privacy.

The section explores open access to government data, particularly in the context of freedom of information laws, as well as the risks of re-identification in disaggregated data. The section further provides examples of how the law has been used to enhance dissemination of disaggregated data through legislative and executive action.

## Government Transparency Laws: Legal Facilitators to Dissemination of Disaggregated Data

Freedom of information laws – sometimes referred to as sunshine laws – require access to any public record upon the request of any person, unless an exception or exemption applies.<sup>197</sup>

### *New York Times v. CDC*

In the early days of the COVID-19 pandemic, the New York Times made a request under the federal Freedom of Information Act (FOIA) seeking data showing the impact of COVID-19 on low-income and minority communities.<sup>198</sup> The Centers for Disease Control & Prevention (CDC) initially denied the request but, after the newspaper filed a lawsuit against the agency, CDC provided county-level data on cases across 974 counties.<sup>199</sup> The data provided a detailed look at almost 1.5 million infected individuals and led to a staggering conclusion, published on the front page of the New York Times on July 6, 2020: “Black and Latino people have been disproportionately affected by the coronavirus in a widespread manner that spans the country, throughout hundreds of counties in urban, suburban and rural areas, and across all age groups.”<sup>200</sup>

Although there was significant and justifiable opposition to the release of identifiable information from state, Tribal, local and territorial health departments, the New York Times case illustrates how **the availability of disaggregated data to the public through freedom of information requests plays a crucial role in revealing health inequities**. It further shows the

The availability of disaggregated data to the public through freedom of information requests plays a crucial role in revealing health inequities.



role of freedom of information requests in government accountability and transparency. Freedom of information requests and lawsuits have prompted CDC to expand data that is open to all, stating in a letter to state and territorial epidemiologists on August 28, 2020:

[i]t has become clear, from the numerous inquiries and Freedom of Information Act requests, that the current public use dataset is insufficient to meet the public’s legitimate interest in data about the pandemic. In response, CDC has worked to create an updated, deidentified public use dataset<sup>201</sup> that includes more information, while fulfilling CDC’s vital obligation to safeguard the privacy of personally identifiable information (PII).<sup>202</sup>

For this de-identified dataset, there was a need for negotiations with jurisdictions regarding the level of data that could be released in order to reduce the risk of re-identification. It is important that processes like this take place in similar situations. With adequate controls to limit re-identification risks, freedom of information laws present the opportunity to provide actionable data to community members to disrupt the transmission or impact of a public health event that may cause morbidity or mortality.

### Freedom of Information Laws


**Q** Every state has a statute similar to the federal FOIA,<sup>203</sup> which mandates, with few specific exceptions, that public records be provided, in short order, to anyone requesting them.<sup>204</sup> State FOIA laws reflect a strong public policy in favor of transparency in government and open public records to public inspection.<sup>205</sup> These laws generally presume that all public records are subject to public inspection. Although framed as public *records* laws, their coverage extends to publicly-held *data*, which is universally considered to be “records” when interpreting freedom of information laws.


California, Louisiana, Montana, New Hampshire, and North Dakota expressly include the public’s right to access government records in their state constitutions.<sup>206</sup> In California, for example, voters amended the state constitution through a ballot initiative in 2004 to include a right of access to government records.<sup>207</sup>

**Q** As the following examples illustrate, **state freedom of information laws differ slightly in exactly what they exempt from disclosure, but generally include privacy-related exemptions** (see **Table 5**).

TABLE 5: STATE FREEDOM OF INFORMATION LAWS

Jurisdiction	Examples of records not required to be released <sup>208</sup>
Ohio	<ul style="list-style-type: none"> <li>Medical records</li> <li>Information prohibited from release by other law<sup>209</sup></li> </ul>
Nebraska	<ul style="list-style-type: none"> <li>Medical records</li> <li>Data submitted to Nebraska’s prescription drug monitoring program<sup>210</sup></li> </ul>
Tennessee	<ul style="list-style-type: none"> <li>Individually identifiable health information collected, created, or prepared by the department of health<sup>211</sup></li> </ul>
New York	<ul style="list-style-type: none"> <li>Records which “if disclosed would constitute an unwarranted invasion of personal privacy”<sup>212</sup></li> </ul>
Illinois	<ul style="list-style-type: none"> <li>Information that is barred from disclosure by federal or state law</li> <li>Private information, including unique identifiers and medical records<sup>213</sup></li> <li>Information that is “highly personal or objectionable to a reasonable person and in which the subject’s right to privacy outweighs any legitimate public interest in obtaining the information”<sup>214</sup></li> </ul>
California	<ul style="list-style-type: none"> <li>Records, if the public agency can show the public interest in disclosing the particular records to the public is outweighed by a public interest in not disclosing the records<sup>215</sup></li> </ul>

 Because government data is presumptively public, government agencies seeking to withhold data in response to a FOIA request bear the burden of establishing that the disclosure is subject to an exception found within the relevant freedom of information law.

 Where there is a measurable risk of re-identification, public health attorneys and practitioners should consider exemptions which are commonly applied to withhold identifiable public health data. These include exemptions for private information, personal information the release of which would constitute a clearly unwarranted invasion of privacy, and information not subject to disclosure under another law. If a FOIA request is denied, most states require a response in writing that clearly articulates the reasons for the denial, including the factual basis supporting the application of any exemption or exception the government claims.<sup>216</sup> **Thus, it is important for public health attorneys and practitioners to be familiar with the exemptions in their jurisdiction’s freedom of information law.** If no exemption applies, public policy requires that the information be released on request.

## FOIA FAQ

**Question: How should a local or state health department handle a FOIA request for data that is protected by a privacy law?**


**Answer:** Whether data protected by privacy law is subject to disclosure under a freedom of information law requires careful legal analysis. Public health attorneys and practitioners in such situations should determine whether an exception or exemption under their jurisdiction’s freedom of information law may be applied.<sup>217</sup> In 2020, an Illinois appellate court faced with such a question held that ZIP codes derived from mental health records were protected health information (PHI) barred from disclosure under a state mental health privacy law. Therefore, they were not subject to disclosure under the state’s freedom of information law that exempted information prohibited from release by another law.<sup>218</sup>

## Risks of Re-identification

The risk of re-identification has been described as “the ability for an interested adversary to use reasonable effort to match details in the de-identified dataset to distinct persons sufficiently to contact them.”<sup>219</sup> Said differently, re-identification is the ability to use data from a de-identified dataset to identify individuals. Whether disaggregated data may be disseminated publicly is often a question of whether, and to what extent, the data presents a risk of re-identification of individuals who are the subject of the data. Thus, we turn now to an analysis of the risk of re-identification in disaggregated data.

### De-identification of Data

We start our analysis of re-identification risks by discussing de-identification.

 **De-identified datasets have not traditionally presented privacy concerns and have been disseminated with far greater ease and frequency than those that include identifiers.** Data that is properly de-identified generally will not meet an unwarranted invasion of personal privacy standard for FOIA purposes, as an example.

The Health Insurance Portability and Accountability Act's (HIPAA) Privacy Rule allows two methods for de-identifying protected health information:<sup>220,221</sup>


1. First is HIPAA's expert determination method.<sup>222</sup> A covered entity can use an appropriate expert familiar with generally accepted statistical and scientific principles and methods for rendering information not individually identifiable to determine that there is no more than a “very small” risk of re-identification. This expert may be someone with appropriate qualifications on staff within the agency.
2. Second is HIPAA's “Safe Harbor” provision,<sup>223</sup> which requires removal of 18 specified identifiers (see **Table 6** below), including date information more specific than the year and geography data smaller than a state (with an exception allowing for most 3-digit ZIP codes with populations of at least 20,000 individuals).<sup>224</sup> Other demographic information, including race and ethnicity, gender identity, marital status, and ages in years up to age 89, are not included in the 18 identifiers that must be removed.<sup>225</sup> In addition to removing the 18 identifiers, the covered entity must not have actual knowledge that any remaining information could be used alone or in combination with other information to identify an individual.<sup>226</sup>

Whether disaggregated data may be disseminated publicly is often a question of whether, and to what extent, the data presents a risk of re-identification of individuals who are the subject of the data.



**TABLE 6: IDENTIFIERS TO BE REMOVED UNDER HIPAA'S SAFE HARBOR DE-IDENTIFICATION METHOD<sup>227</sup>**

<b>A</b>	Names
<b>B</b>	All geographic subdivisions smaller than a state, except for the initial three digits of a ZIP code in limited circumstances
<b>C</b>	All elements of dates (except year) for dates directly related to an individual
<b>D</b>	Telephone numbers
<b>E</b>	Fax numbers
<b>F</b>	Electronic mail addresses
<b>G</b>	Social security numbers
<b>H</b>	Medical record numbers
<b>I</b>	Health plan beneficiary numbers
<b>J</b>	Account numbers
<b>K</b>	Certificate/license numbers
<b>L</b>	Vehicle identifiers and serial numbers, including license plate numbers
<b>M</b>	Device identifiers and serial numbers
<b>N</b>	Web Universal Resource Locators (URLs)
<b>O</b>	Internet Protocol (IP) address numbers
<b>P</b>	Biometric identifiers, including finger and voice prints
<b>Q</b>	Full face photographic images and any comparable images
<b>R</b>	Other unique identifying number, characteristic, or code

 **Although not all data, nor even all health data, is PHI subject to HIPAA, expert determination and the Safe Harbor provide methods of de-identification that can be, and frequently are, applied outside the context of HIPAA.**

In particular, the Safe Harbor method presents a black-letter-law approach that can be uniformly applied to different datasets by someone without expert training in statistical methods. Thus, where other laws are often silent as to exactly what constitutes de-identified data, the Safe Harbor and expert determination methods are models that may be used or adapted.

The use of HIPAA's de-identification standards presents certain drawbacks, however. The expert determination method is complex, requiring a qualified expert to apply scientific methods. The Safe Harbor method can be overly harsh because it requires removal of important dates and geographic details. Some of the data that is legally and routinely made available on public health data portals would not pass muster under the Safe Harbor method because of a tendency and need to include geographic subdivisions such as counties, ZIP codes, or census tracts. This has been illustrated throughout the COVID-19 pandemic as health departments, employing hyper-focused interventions to inform and protect the communities they serve,<sup>228</sup> have made publicly available rates of infections, deaths, and vaccinations at the community level, including 5-digit ZIP Codes.<sup>229</sup> In addition, the federal government requests reporting of line level data from state and local health departments that contain some of the 18 variables referenced in the Safe Harbor method.

## Risk of Re-identification from Disaggregated Data

**Q** Although race and ethnicity are not direct identifiers, they can be thought of as quasi-identifiers, owing to the potentially significant increase in risk of re-identification. Quasi-identifier data elements like race and ethnicity are not designated for exclusion by the Safe Harbor method, even though they can provide additional information which, when used in combination, can increase the risk of re-identification for individuals in the dataset (Figure 4). Such risks can be realized through linkage with demographic characteristics which are often found in external datasets and, thus, can be used to create re-identifying links to personal identifiers such as name, address, or other “directly identifying” data elements.

**Q** Re-identification risks from race and ethnicity data can vary dramatically from one state to another, and even within different areas of a state depending on the geographic distributions of racial and ethnic groups. Further, re-identification risks increase with the presence of additional quasi-identifier demographic characteristics (age, gender, marital status, etc.) in public health datasets and become greater when the data discloses areas with smaller populations. In combination with additional details, such as dates that are a matter of public record (e.g., birth or death dates) or gender, race and ethnicity can help uniquely characterize individuals within the data. When more detailed racial and ethnic categories are utilized (for example, the 39 distinct racial/ethnic categories designated under the Oregon Race, Ethnicity, Language, and Disability (REALD) law,<sup>230</sup> as compared to the current more limited Office of Management and Budget (OMB) Directive No. 15 racial and ethnic classifications), the potential risks of re-identification can be dramatically increased.

To make matters worse, legal minds, including judges, frequently disagree on the risk of re-identification.<sup>231</sup> In a recent case, a majority of the Wisconsin Supreme Court affirmed the dismissal of a challenge to the state’s production of records listing certain businesses with two or more COVID-19 cases, opening the door to the release of the information.<sup>232</sup> The chief justice, in a dissenting opinion, strongly disagreed, arguing the majority’s decision essentially sanctioned disclosure of private medical information of the individuals who had had COVID-19.<sup>233</sup>

**Q** While, in practice, there may be points of disagreement among public health professionals, lawyers, and judges about potential risks of re-identification, HIPAA’s expert determination method<sup>234</sup> provides a reasoned basis for responsible management of re-identification risks while balancing these risks with the need for disaggregated data. Statisticians trained in disclosure risk assessment and limitation methods can suggest possible modifications to the released data that will reduce re-identifications to acceptable thresholds while maximizing the data’s utility for the desired purposes. For example, when more detail is required regarding racial/ethnic categories, the level of detail can be reduced for other quasi-identifiers. Such trade-offs to assure very small re-identification risks might be achieved, for example, by:

- Providing age groups instead of age in years,
- Increasing the size of the geographic reporting units,
- Collapsing certain geographic areas together, or
- Selectively censoring race/ethnicity in areas where too few individuals exist to allow safe reporting (see **Figure 4** for additional information on these risks).

To more readily and easily render data de-identifiable, and thereby promote dissemination of disaggregated data, state and local health departments should invest resources to:

- ★ ■ **Recruit individuals familiar with generally accepted statistical and scientific principles and methods for rendering information not individually identifiable, and/or train appropriately qualified staff on such principles and methods.**
- **Train all appropriate staff on the Safe Harbor method.**
- ★ ■ **Federal agencies, such as the Centers for Medicare and Medicaid Services (CMS) and CDC, should consider broadening policy to include incentives and support for training public health authority staff in statistical disclosure risk assessment and control to facilitate reporting of race and ethnicity data.**

## Dissemination and Privacy

Q The dissemination of disaggregated data is key to identifying and reducing health inequities.<sup>235</sup> At the same time, **failing to protect the privacy of individuals has the potential to actually harm members of underserved subpopulations or Tribal nations who may be at heightened risk of harm if their privacy is compromised.**<sup>236</sup> This creates a tension between the need to make available accurate and specific disaggregated data and the need to maintain the confidentiality and privacy protections of individuals whose identity could be revealed.<sup>237</sup> Public health practitioners engaged in data disaggregation therefore find themselves at the crossroads of transparency and protecting the privacy of the individuals whose data is collected.

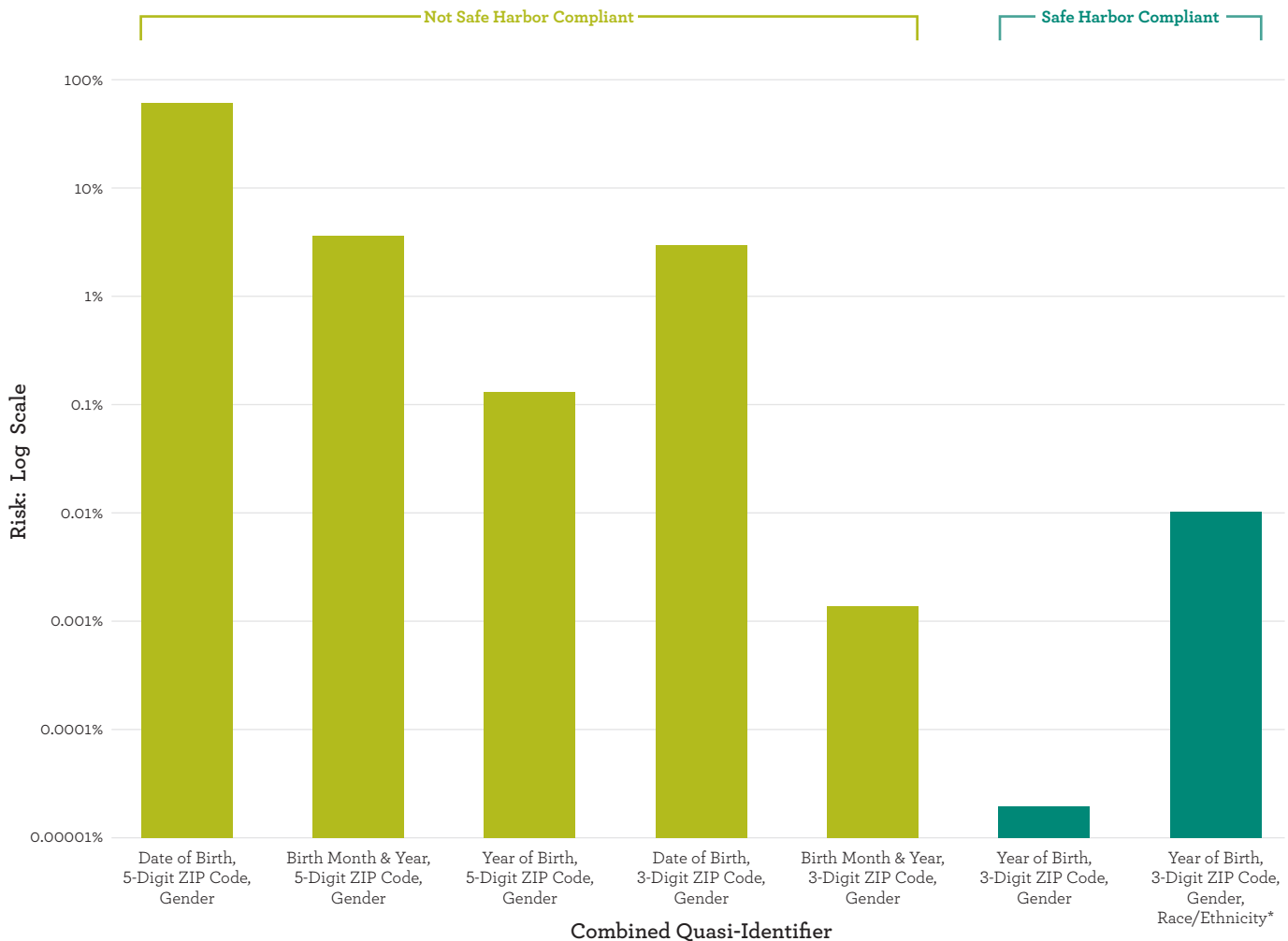
State public health reporting laws include provisions governing how the collected data may be disclosed (discussed in **Section 2**). Some states also have general privacy protections that may be applicable to dissemination of disaggregated data. Some emphasize the privacy interests of the people whose information has been collected and say that information cannot be released if re-identification is at all possible.<sup>238</sup> Others emphasize the value of data and expressly allow the disclosure of statistical information so long as re-identification risk is sufficiently limited. Consequently, different jurisdictions may come to differing conclusions about whether and what public health data elements can be released to the public.

## De-identification and Re-identification FAQ

**Question: Must I remove race and ethnicity data when de-identifying PHI under HIPAA using the Safe Harbor method?**

**Answer:** Not necessarily. The Safe Harbor method requires removal of 18 different identifiers. Race and ethnicity are not identifiers that have to be removed under the Safe Harbor method. That said, the Safe Harbor method requires that even if all 18 identifiers have been removed, the covered entity cannot have *actual* knowledge that the information – such as race or ethnicity – could be used alone or in combination with other information to identify an individual who is a subject of the information. Thus, even after removing all 18 identifiers, the inclusion of race and ethnicity in some instances, such as in smaller communities, or communities in which there is a small number of individuals of certain races or ethnicities, may not de-identify the data.

FIGURE 4: RE-IDENTIFICATION RISKS: MEDIAN POPULATION UNIQUENESS



\* White, Black, Hispanic, Asian and Other

Data source: 2010 U.S. Decennial Census | Graph kindly provided by Daniel Barth-Jones, PhD, MPH ©2013

#### Population uniqueness is an important measure of re-identification risk.

This graph illustrates population uniqueness calculated as the proportion of people who could be potentially re-identified through their unique combination of the quasi-identifier characteristics listed under each bar. The population uniqueness is presented on a log scale, so each demarcation on the scale represents one tenth of the re-identification risk for the demarcation on the scale above it. While each quasi-identifier characteristic would not directly re-identify an individual when used on its own, combinations of the quasi-identifiers can render a person unique and, therefore, potentially re-identifiable. This graph presents the median of the population uniqueness proportions as calculated for all 50 states, plus Washington, DC and Puerto Rico for each set of “quasi-identifier” characteristics. Gender is included as a quasi-identifier for all population-uniqueness calculations presented. As the resolution for individual’s birth date information or their geographic location decreases, the population uniqueness decreases resulting in lower re-identification risks. However, as illustrated, racial disaggregation adds additional information which can render individuals unique within their locations and can substantively increase potential re-identification risks.

- 🔍 Myriad and complex privacy laws can have an unintended chilling effect on dissemination of data when health departments and others, concerned about violating the law, incurring potential fines, and undermining public trust that data is protected, withhold data that should otherwise be shared. Further, decisions and procedures to determine which data to share and how to de-identify or protect it use up valuable staff resources and are very difficult for staff without sufficient expertise in these areas. **State and local health departments should establish clear:**
  - Policies and procedures on data dissemination that include explicit criteria, consistent with applicable law, for staff to reference in determining whether to grant data requests,
  - Data suppression guidelines/criteria, and
  - Policies and procedures on open data release.
- ★ Lawmakers should also take note of the ever-growing patchwork of public-health-related privacy law and create policy solutions that foster a more cohesive approach to data privacy.

## Dissemination and Privacy FAQ

**Question: Do privacy laws prohibit the dissemination of disaggregated data?**

**Answer:** If the disaggregated data is truly de-identified, privacy law generally does not prohibit dissemination. However, even where data has been de-identified, there may still be some small risk of re-identification, in which case the answer may not be as clear. Statisticians trained in disclosure risk assessment and limitation methods can assess the possible re-identification risks and suggest possible modifications to the data that will reduce re-identifications to acceptable thresholds.

## State Privacy Laws and Public Dissemination

Some states have general privacy protections that may be applicable to dissemination of disaggregated data:

- Tennessee's Medical Records Act<sup>239</sup> is similar to HIPAA and creates a right to medical privacy.
- Texas also has a Medical Privacy Act that protects health information its health department possesses.<sup>240</sup>
- Pursuant to Nebraska state law, the Nebraska Department of Health and Human Services cannot publicly disclose data that identifies anyone,<sup>241</sup> and recipients of data are legally prohibited from intentionally re-identifying people.<sup>242</sup>
- Similar to the federal Privacy Act,<sup>243</sup> some states like California and New York regulate the collection and release of any type of identifying information by their state agencies.
  - In California, the Information Practices Act of 1979<sup>244</sup> bars agencies from disclosing personal information in a manner that would link the information to the person to whom it pertains.
  - In New York, state agencies are prohibited from releasing identifying data by the Personal Privacy Protection Law.<sup>245</sup>

# USE OF LAW AND POLICY TO PROMOTE OPEN DATA

When used correctly, the law can enhance dissemination of disaggregated data. As illustrated by the examples below, legislative powers and executive authority have been used creatively to do so:

- In 2012, then-mayor of the City of Chicago, Rahm Emanuel, issued an executive order establishing a city data portal and requiring all agencies of the city’s government to publicly post all available appropriate datasets under the agency’s control.<sup>246</sup> The executive order created a single City-wide datahub and set requirements for the format of data posted on the datahub.<sup>247</sup>
- In 2013, President Obama signed an executive order “advancing management of government data as an asset,” and making open and machine readable the new default for federal government information.<sup>248</sup>
- President Joseph R. Biden issued an executive order on January 21, 2022, designed to improve collection and dissemination of data, including key equity indicators, to help fight COVID-19 and future high consequence public health threats.<sup>249</sup> Among other things, the order required the Director of the OMB to issue guidance on “how to make data open to the public in human- and machine-readable formats as rapidly as possible.”<sup>250</sup>
- On April 22, 2020, the State of New Jersey enacted a statute requiring the State’s Department of Health to publish COVID-19 hospital patient demographic data, including age, race, ethnicity and gender, on its website.<sup>251</sup> The statute is significant because it requires publication of data elements by county and municipality – both of which are geographic subdivisions smaller than a state, and would typically have to be removed under HIPAA’s Safe Harbor de-identification method.
- Sixteen states have laws that mandate data be made available in open data formats.<sup>252</sup> Many of these laws mandate that data be cataloged and require establishment of open data portals.<sup>253</sup>
- Governments on all levels – federal, state, local and international – are increasingly establishing open data portals to make mainly de-identified datasets more freely accessible. As of this writing, the federal government’s data.gov website lists 48 states, 48 U.S. cities and counties, 53 countries and 165 international regions with open data sites.<sup>254</sup>



Section 5.

# Data Sharing Between Governments and Other Partners

Public access to disaggregated data is essential to effective public health practice. However, access to disaggregated – and in many instances identifiable – data by public health partners is also necessary.

While **Section 4** explored legal issues in *public* dissemination of data, this section of the handbook explores legal issues when sharing data with partners, including among state and local health departments, Tribes, and non-government partners.

Intergovernmental data sharing between state, Tribal, local, and federal agencies supports public health programming. The type of data being shared can vary substantially to include fully identifiable, de-identified, aggregated, or disaggregated data, or a combination thereof. While a variety of federal laws implicate data sharing,<sup>255</sup> Health Insurance Portability and Accountability Act (HIPAA) and state privacy laws are often the primary concerns for state and local health departments. This section considers how these privacy laws affect data sharing with local governments, Tribal governments, and other partners. See **Figure 1** for additional information on the audiences for public health data sharing.

Intergovernmental data sharing between state, Tribal, local, and federal agencies supports public health programming.

## Data Sharing and Privacy Laws

As discussed above in **Section 3**, HIPAA's Privacy Rule allows a covered entity to disclose protected health information (PHI) to a public authority authorized to receive the information for public health purposes.<sup>256</sup> A covered entity that is also a public health authority is permitted to use PHI in all instances in which it would be permitted to disclose the information to a public health authority.<sup>257</sup>

**Q** **At the state level, the law varies substantially in the context of intergovernmental data sharing.** Some state laws explicitly authorize the disclosure of public health data for public health purposes.<sup>258</sup> States may also adopt data sharing laws specific to certain types of health information, such as communicable diseases or prescription drugs.<sup>259</sup> Some states, including Indiana, have codified a mechanism for intra-agency, state-to-state and state-to-local, data sharing.<sup>260</sup> Depending on the circumstances, data use agreements may facilitate data sharing and can represent a best practice. This is particularly true in states that allow data sharing for public health purposes but do not specify the agencies with which data can be shared.



- ★ **When assessing whether data can be shared with another government agency, jurisdictions should consider which laws apply to the data and whether these laws explicitly or implicitly permit sharing the data.**

Given gaps in COVID-19 data access, jurisdictions have implemented measures to facilitate intergovernmental data sharing. For example, President Biden's January 2021 executive order specifically seeks to improve data sharing between the federal government and state, local, Tribal, and territorial governments.<sup>261</sup> And, Georgia Governor Brian Kemp issued an executive order on November 20, 2020, suspending any state laws or regulations that would prohibit disclosure of individually identifiable health information to HHS.<sup>262</sup>

## Data Sharing with Local Governments

- 🔍 **Even before COVID-19, a 2019 national profile of local health departments (LHDs) revealed that they actively exchange data with multiple health care, government, and community-based partners.**<sup>263</sup> Within healthcare alone, 60% of LHDs received data from hospitals and 57% sent data to hospitals.<sup>264</sup> LHDs also exchanged data with physician practices, mental health/substance use providers, emergency responders, community health centers, local planning agencies, the criminal justice system, housing, K-12 schools and community-based non-profits, among others.<sup>265</sup>

- 🔍 **Although LHDs need timely and accurate data to most effectively direct public health interventions, collection of public health data is often controlled by state law, which frequently requires reporting of data to state agencies.** This reporting route, from data reporters directly to state databases, can bypass LHDs and result in significant lag times for gaining access to data about its own residents. In some cases, LHDs are not permitted access to the data at all. In Illinois, for example, the state's Controlled Substances Act requires reporting of prescription monitoring data to a central repository created by a state agency, and permits disclosure of that data to licensing bodies and law enforcement, but not to LHDs.<sup>266</sup>

- ★ **LHDs wishing to more easily exchange data with partners may consider master data sharing agreements that permit ongoing data sharing through the addition of data-exchange-specific task orders or appendices. They may also consider exercising their authority to require certain data exchanges, such as through an ordinance or executive order.** The Municipal Code of the City of Chicago, for example, requires any individual required to report data to a local, state, or federal agency, to also provide the data to the City's Commissioner of Health on request, except where such disclosure would not be permitted by law.<sup>267</sup> **LHDs may also explore participating in health information exchanges and incentivizing partners to participate in such exchanges.** In 2021, for example, having committed to racial justice and health equity as priorities, the County of San Diego conditioned letters of support for applicants to the state's managed care plan procurement process on a commitment to participate in the local community information exchange (CIE)<sup>™</sup>.<sup>268</sup>

Although local health departments need timely and accurate data to most effectively direct public health interventions, collection of public health data is often controlled by state law, which frequently requires reporting of data to state agencies.

## Data Sharing with Tribal Governments

Tribes are sovereign nations with public health authority for their people. Further, federal law recognizes Tribes as public health authorities under HIPAA alongside state and local health departments.<sup>269</sup> **Tribal nations have the authority and jurisdiction to engage in intergovernmental collaboration and coordination to promote public health in their communities and among their neighbors.** In the context of public health surveillance and data disaggregation, there are unique considerations for state governments when working with Tribal governments.

- Q** Unfortunately, states frequently deny Tribal access to data they would otherwise make available to state and local health departments.<sup>270</sup> State reporting systems often bypass Tribal health departments and result in delays for Tribes to access data about their residents. Like any other government, having timely access to disaggregated or identifiable information is essential for Tribes to craft appropriate public health interventions. This is particularly true given that many Tribal members may live far from Tribal lands and that race, coupled with other information such as location, is used as a proxy in lieu of Tribal membership for a specific Tribe's public health surveillance efforts. To assess community health risks for their members, Tribes may also need public health data related to all races, not just American Indians and Alaska Natives. **State law and policy that hinders Tribal data sharing needs to be removed or amended and Tribes should have at least as much access as any other public health authority. State and local governments should partner with Tribes through data sharing agreements, MOUs, or other arrangements to facilitate this exchange.**
- ★** State and local governments should also consider that the collection and sharing of identifiable or disaggregated data can affect Tribal sovereignty. First, the collection of race and ethnicity data is different from the collection of Tribal membership information. Following a systematic review of American Indian and Alaska Native decedents on state death certificates, Professors Small-Rodriguez and Akee found no standardized collection method for Tribal membership. This means that **disaggregated data can implicate one or more Tribes without a mechanism to identify any particular Tribe.** Because of this, disaggregated data may be less meaningful to Tribes than identifiable data. At the same time, Tribes have an interest and authority to respond to public health issues within their jurisdiction, including those involving non-member residents and visitors. For example, if a Tribal government is experiencing a communicable disease outbreak on Tribal lands, it is imperative that the Tribe have direct access to this data to respond quickly and efficiently.

## California Data Exchange Framework

California has recently taken a novel approach to enhancing exchange of health and human services data among health care entities, government entities and social service programs. AB133, signed by California Governor Gavin Newsom on July 27, 2021, requires the California Health and Human Services Agency (CalHHS) to establish a Data Exchange Framework by July 1, 2022.<sup>271</sup> The Framework will involve a single state-wide data use agreement and common set of policies and procedures that will require data exchange among health care entities and government agencies.<sup>272</sup> Many California health care entities are required to sign the data use agreement by January 31, 2023.<sup>273</sup> The law also expresses the legislature's intent that "all state and local public health agencies will exchange electronic health information in real time with participating health care entities" to protect the public health. It also requires CalHHS to encourage county public health and social services agencies to participate in the framework.<sup>274</sup>

Second, public health surveillance also implicates **Indigenous data sovereignty**. Indigenous data is defined as “any facts, knowledge, or information about a Native nation and its tribal citizens, lands, resources, cultures, and communities. Information ranging from demographic profiles to educational attainment rates, maps of sacred lands, songs, and social media activities.”<sup>275</sup>

**There is a long history of governments, researchers, and private organizations using Indigenous data to leverage their own goals at the expense of Tribal communities. Indigenous data sovereignty ensures the right of Tribes “to govern the collection, ownership, and application of their own data.”**<sup>276</sup> Tribes may have concerns with other governments collecting and disseminating disaggregated data that implicates their citizens, including specific collection practices where individuals identify their Tribal membership or when data is shared in a way that is interpreted to represent the entire Tribe. Thus, each Tribe needs to be able to determine if and how Tribal membership information is collected in various public health data systems.

**Finally, despite the need for disaggregated data, collecting it runs the risk of re-identification, as discussed in Section 4, which can create particular harms for Tribal communities.** If Tribal membership is included in data collection systems, then re-identification risks would increase.

State and local governments can be effective partners to Tribal governments when considering data disaggregation efforts. States can ensure that the collection, distribution, and presentation of Indigenous data is done in

accordance with their Tribal partners. **To avoid undermining Tribal public health authority and programming, states should engage in rigorous consultation with Tribes and enter into intergovernmental data sharing agreements where appropriate.** The National Congress of American Indians, in collaboration with other organizations, recently offered its recommendations for state health data and disaggregation:

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

**Consultation is a formal, government-to-government process that ensures free, prior, and informed engagement with Tribes before taking actions.** Through intergovernmental agreements, gubernatorial executive orders, and statutes, some states require consultation with Tribal governments. These laws vary in the substantive scope and rigor of their consultation requirements.<sup>277</sup> Washington State’s intergovernmental agreement requires the state to develop consultation policies and processes.<sup>278</sup>

**Consultation is a formal, government-to-government process that ensures free, prior, and informed engagement with Tribes before taking actions.**

Other states have broad consultation requirements. State agencies in Oregon<sup>279</sup> and New Mexico,<sup>280</sup> for example, are required to make “reasonable efforts” to collaborate with Tribes. Following consultation, states can document their updated processes via intergovernmental agreements with Tribes and Tribal Epidemiology Centers (TECs) to facilitate health data sharing. Some states have Tribal liaison offices within their agencies or have state-level commissions to work on issues involving Native American affairs.

State and local governments may also partner with Tribal-serving organizations, such as TECs and urban Indian health programs. In consultation with Tribes,<sup>281</sup> the 12 TECs located across the country<sup>282</sup> support public health surveillance and programming across Indian Country.<sup>283</sup> As with Tribes, TECs are regularly denied access to important public health data.<sup>284</sup> Importantly, federal law defines TECs as public health authorities under HIPAA, permitting covered entities to disclose PHI for their public health work.<sup>285</sup> Likewise, there are over 40 urban Indian health programs<sup>286</sup> housed at Urban Indian Organizations that contract with the federal government to provide direct health services and engage in public health surveillance.<sup>287</sup>

## Data Sharing with Partners

Health departments may also be a source of data for research. Data requesters include universities or non-governmental organizations that might be working in partnership with a health department or another governmental entity. **To assess whether data may be shared with these entities, health departments must first examine what data is requested (i.e., is it fully identifiable, de-identified, aggregated, disaggregated, or a combination) and the purpose for the request. Next, they must assess the laws surrounding the data requested to determine if the data – in the format requested or another format – may be disclosed to the requestor. Third, assuming legal authority to share the data, health departments should assess whether the project is something it wishes to support (i.e., are there ethical or equity considerations). Finally, if a determination is made that data sharing is appropriate, health departments should strongly consider executing a data sharing or data use agreement with the requester that outlines the terms and conditions of how the data may be used and must be protected.**

**Section 4** addresses many of the privacy considerations a health department must assess when evaluating a research data request. For example, does state law allow data to be disclosed? In what format? **Health departments should also assess whether any federal law – such as the law protecting substance use records – is applicable.** If the data is covered by HIPAA, health departments must then assess the purpose for the disclosure and whether it is covered by one of HIPAA’s permitted disclosures or whether written authorization to disclose is required. One potential avenue within

HIPAA is the Privacy Rule's permitted disclosures for research – an exception to the written authorization requirement – which permits disclosures when certain criteria are met.<sup>288</sup> If data requested is for human subjects research, then Institutional Review Board (IRB) review and compliance with federal human subject research laws may be required.<sup>289</sup>

★ **Lastly, health departments must consider the request against its own internal policies and procedures.**

## Data Sharing Agreements

Data use or sharing agreements play an important role in dissemination of non-public data. The agreements can take many forms and can vary in formality and complexity – ranging from non-binding memoranda of understanding to complicated and legally-binding data sharing agreements. Using data sharing agreements to put terms and conditions around disclosures is a best practice, especially with non-governmental requesters, even if the law does not require it. Data sharing agreements should

clearly identify the data holder(s), data recipient(s), data source, data elements, legal authority to share data, terms of the recipients use or further disclosure of data, and the safeguards in place that will protect the data from unauthorized use or disclosure. In addition, the agreement should clearly outline procedures in the event data is used or disclosed inconsistent with the agreement and whether the data must be returned or destroyed upon completion of the agreement.



# Conclusion



Collection of and access to disaggregated data alone will not end inequitable health outcomes. Yet, it is an essential first step. With accurate and complete health data, policymakers can be better

equipped to interpret and use data to dismantle the legal, social, political, and economic systems that create inequities in the first place.

Law underpins our existing public health surveillance systems and must be assessed when determining mechanisms to facilitate data collection, disaggregation, and dissemination. As outlined throughout this handbook, there are a variety of nuanced considerations and opportunities to both improve the collection and dissemination of race and ethnicity data in public health to inform and address inequities. Our hope is that this handbook demystifies the current legal landscape and identifies opportunities to use the law to improve data collection and dissemination.



# Appendices





# Appendix 1: Glossary of Key Terms

## **Confidentiality**

Confidentiality refers to the obligations of individuals or groups who receive or use information to respect the privacy interests of individuals who are subjects of the data.

## **Data Aggregation**

Data aggregation refers to collecting data from multiple sources and/or on multiple measures, variables, or individuals and compiling the data into summaries or summary reports, typically for the purposes of public reporting or statistical analysis – i.e., examining trends, making comparisons, or revealing information and insights that would not be observable when data elements are viewed in isolation.<sup>290</sup>

## **Data Disaggregation**

Data disaggregation refers to the separation of compiled information into smaller units to elucidate underlying trends and patterns. Compiled data may come from multiple sources and have multiple variables or “dimensions.” To enhance understanding of a situation, the data is grouped by dimension, such as age, sex, geographic area, education, ethnicity, or other socioeconomic variables.<sup>291</sup>

## **De-identified Data**

De-identified data is data that has been subject to methods for rendering it not individually identifiable, such as the removal of personal identifiers including, but not limited to, name, address, telephone number, social security number, health identification number, and other identification numbers, thereby greatly reducing the risk of disclosure.

## **Ethnicity**

Ethnicity is a social construct that divides people into smaller social groups based on characteristics such as shared sense of group membership, values, behavioral patterns, language, political and economic interests, history, and ancestral geographical base.<sup>292</sup>

## **Health Inequities**

Health inequities are systematic differences in the opportunities groups have to achieve optimal health, leading to unfair and avoidable differences in health outcomes. The dimensions of social identity and location that organize or “structure” differential access to opportunities for health include race and ethnicity, gender, employment and socioeconomic status, disability and immigration status, geography, and more.<sup>293</sup>

## **Indigenous Data Sovereignty**

Indigenous data is defined as “any facts, knowledge, or information about a Native nation and its tribal citizens, lands, resources, cultures, and communities. Information ranging from demographic profiles, to educational attainment rates, maps of sacred lands, songs, and social media activities.”<sup>294</sup> Indigenous data sovereignty ensures the right of Tribes “to govern the collection, ownership, and application of their own data.”<sup>295</sup>

## **Intersectionality**

Intersectionality is inquiry and praxis (action and reflection) for advancing equity and justice in policy, practice and distribution of resources. “Intersectionality is a way of understanding and analyzing complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people’s lives and the organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other.”<sup>296</sup>

## **Privacy**

Privacy as it relates to health information broadly refers to individuals’ rights to control the acquisition, uses, or disclosure of their identifiable health data.

## **Public Health Surveillance**

Public health surveillance is the ongoing, systematic collection, analysis, and interpretation of health-related data essential to planning, implementation, and evaluation of public health practice.<sup>297</sup>

## **Race**

Race is a socially constructed system of categorizing humans largely based on observable physical features (phenotypes), such as skin color, and on ancestry. There is no scientific basis for or discernible distinction between racial categories.<sup>298</sup>

## **Re-identification**

Re-identification is “the ability for an interested adversary to use reasonable effort to match details in the de-identified dataset to distinct persons sufficiently to contact them.”<sup>299</sup>

## **Security**

Security as it relates to data refers to physical, technical, and administrative safeguards designed to protect identifiable health data from unwarranted access or disclosure.

## **Social Determinants of Health**

Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.<sup>300</sup>

# Appendix 2: Selected Data Disaggregation Reports and Resources

**Asian & Pacific Islander American Health Forum (APIAHF), Advocating for data disaggregation by race and ethnicity** (2021) (last visited Oct. 30, 2022).

**Asian & Pacific Islander American Health Forum, (APIAHF), Policy Recommendations: Health Equity Cannot Be Achieved Without Complete and Transparent Data Collection and the Disaggregation of Data** (last visited Oct. 30, 2022).

**Council of State and Territorial Epidemiologists (CSTE), Addressing Gaps in Public Health Reporting of Race and Ethnicity Data for COVID-19: Findings & Recommendations Among 45 State & Local Health Departments** (2022) (last visited Oct. 30, 2022).

**Croal Services Group, Identifying Governmental Public Health Systems Barriers and Facilitators to Complying with and Expanding Race and Ethnicity Data Disaggregation Standards** (2022) (last visited on Oct. 30, 2022).

**Commission on Evidence-Based Policymaking, The Promise of Evidence-Based Policymaking** (Sept. 2017) (last visited Nov. 12, 2022)

**Grantmakers In Health (GIH) & National Committee for Quality Assurance (NCQA), Federal Action is Needed to Improve Race and Ethnicity Data in Health Programs** (2021) (last visited Oct. 30, 2022).

**Grantmakers In Health (GIH), Improving Data on Race and Ethnicity: A Roadmap to Measure and Advance Health Equity** (2021) (last visited Oct. 30, 2022).

**Amy Hawn Nelson et al., Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration Actionable Intelligence for Social Policy, Expert Panel Report** (2022) (last visited Oct. 30, 2022).

**Aila Hoss, Tribes Are Public Health Authorities: Protecting Tribal Sovereignty in Times of Public Health Crisis** (2021) (last visited Oct. 30, 2022).

**Kimberly R. Huyser et al., Covid-19 Pandemic and Indigenous Representation in Public Health Data** (2021) (last visited Oct. 30, 2022).

**The Leadership Conference Education Fund, Information Nation: The Need for Improved Federal Civil Rights Data Collection** (2022) (last visited Oct. 30, 2022).

**National Network of Health Surveys Workshop Series, Advancing Health Equity Through Data Disaggregation: Legal and Regulatory Guidance for Racial/Ethnic Data Disaggregation in Health Data Sets** (last visited Oct. 30, 2022).

**Kevin Nguyen, Disaggregating Asian American and Pacific Islander Health Data: Opportunities to Advance Health Equity** (2022) (last visited Oct. 30, 2022).

**Northwest Portland Area Indian Health Board, NativeDATA** (last visited Oct. 30, 2022).

**Office of Management and Budget, Federal Data Strategy – A Framework for Consistency** (last visited Oct. 30, 2022).

**Oregon Health Authority: Office of Equity and Inclusion: State of Oregon, Race, Ethnicity, Language, and Disability (REALD) Implementation** (last visited Oct. 30, 2022).

**Robert Wood Johnson Foundation, Charting a Course for an Equity-Centered Data System** (2021) (last visited Oct. 30, 2022).

**Robert Wood Johnson Foundation, Get the Full Picture: Advocating for Data Disaggregation by Race and Ethnicity** (December 2020) (last visited Oct. 30, 2022).

**Desi Small-Rodriguez & Randall Akee, Identifying Disparities in Health Outcomes and Mortality for American Indian and Alaska Native Populations using Tribally Disaggregated Vital Statistics and Health Survey Data** (2021) (last visited Oct. 30, 2022).

**The White House, A Vision for Equitable Data: Recommendations from the Equitable Data Working Group** (2022) (last visited Oct. 30, 2022).

**Naima Wong Croal et al., Identifying Systems-level Barriers to Complying with and Expanding National Race & Ethnicity Data Disaggregation Standards Keep It Sacred** (2022) (last visited Oct. 30, 2022).



# Endnotes



1. In this handbook, we use the term data as both a singular and plural noun, as opposed to datum as a singular noun and data as plural. See Candace Osmond, *Data is or Data are? The Singular vs. Plural Debate*, GRAMMARIST, <https://grammarist.com/usage/data/> (last visited Oct. 10, 2022); Microsoft Style Guide: data, datum, MICROSOFT LEARN (June 24, 2022) <https://learn.microsoft.com/en-us/style-guide/a-z-word-list-term-collections/d/data-datum> (last visited Oct. 10, 2022).
2. *Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity*, CTRS. FOR DISEASE CONTROL & PREVENTION (Sept. 15, 2022), <https://www.cdc.gov/coronavirus/2019-ncov/covid-data/investigations-discovery/hospitalization-death-by-race-ethnicity.html>.
3. VICTOR RUBIN ET AL., COUNTING A DIVERSE NATION: DISAGGREGATING DATA ON RACE AND ETHNICITY TO ADVANCE A CULTURE OF HEALTH (2018), [https://www.policylink.org/sites/default/files/Counting\\_a\\_Diverse\\_Nation\\_08\\_15\\_18.pdf](https://www.policylink.org/sites/default/files/Counting_a_Diverse_Nation_08_15_18.pdf).
4. Aila Hoss, *Tribes are Public Health Authorities: Protecting Tribal Sovereignty in Times of Public Health Crisis*, SSRN 2–3 (Jan. 2021), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=3759311&download=yes](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3759311&download=yes) (Issue Brief Prepared for the Great Lakes Inter-Tribal Epidemiology Center); Udall, Murray, Pallone, Grijalva, Gallego Raise Concerns about Tribes Being Denied Access to Critical Federal COVID-19 Data, U.S. SENATE COMM. ON INDIAN AFFS. (July 2, 2020) <https://www.indian.senate.gov/news/press-release/udall-murray-pallone-grijalva-gallego-raise-concerns-about-tribes-being-denied>.
5. *Glossary of Statistical Terms – Disaggregation*, ORG. FOR ECON. COOP. AND DEV. (Jan. 29, 2004) <https://stats.oecd.org/glossary/detail.asp?ID=4337> (last visited Dec. 17, 2021).
6. ANNIE E. CASEY FOUND., *Equity vs. Equality and Other Racial Justice Definitions* (Apr. 14, 2021), <https://www.aecf.org/blog/racial-justice-definitions>.
7. TEACHING FOR DIVERSITY AND SOCIAL JUSTICE: A SOURCEBOOK (Maurianne Adams, Lee Anne Bell, Pat Griffin eds., 1997), <https://www.racialequitytools.org/glossary>.
8. A VISION FOR EQUITABLE DATA: RECOMMENDATIONS FROM THE EQUITABLE DATA WORKING GROUP, <https://www.whitehouse.gov/wp-content/uploads/2022/04/eo13985-vision-for-equitable-data.pdf>.
9. RUBIN ET AL., *supra* note 3.
10. RUBIN ET AL., *supra* note 3.
11. Samantha Artiga et al., *Racial Disparities in COVID-19: Key Findings from Available Data and Analysis*, KAISER FAM. FOUND. (Aug. 17, 2020), <https://www.kff.org/report-section/racial-disparities-in-covid-19-key-findings-from-available-data-and-analysis-issue-brief/>; CHRISTI A. GRIMM, CDC FOUND. WAYS TO USE DATA TO UNDERSTAND AND ADDRESS COVID-19 HEALTH DISPARITIES, DESPITE CHALLENGES WITH EXISTING DATA (U.S. Dep’t of Health and Hum. Servs. Off. of Inspector Gen., 2022), <https://oig.hhs.gov/oei/reports/OEI-05-20-00540.pdf>.
12. Cara V. James et al., *Modernizing Race and Ethnicity Data in Our Federal Health Programs*, THE COMMONWEALTH FUND (Oct. 26, 2021), <https://www.commonwealthfund.org/blog/2021/modernizing-race-and-ethnicity-data-our-federal-health-programs>.
13. Jennifer L. Wiltz et al., *Racial and Ethnic Disparities in Receipt of Medications for Treatment of COVID-19 – United States, March 2020–August 2021*, 71 *Morbidity and Mortality Wkly. Rep.* 96 (Ctrs. for Disease Control & Prevention, 2022), [https://www.cdc.gov/mmwr/volumes/71/wr/mm7103e1.htm?s\\_cid=mm7103e1\\_w](https://www.cdc.gov/mmwr/volumes/71/wr/mm7103e1.htm?s_cid=mm7103e1_w).
14. *Id.* (comparing Black, Asian, and Other race (including American Indian or Alaska Native, Native Hawaiian or Other Pacific Islander, and multiple or Other races) and Hispanic patients with positive SARS-CoV-2 test results relative to White and non-Hispanic patients).
15. *Risk for COVID-19 Infection, Hospitalization, and Death By Race/Ethnicity*, *supra* note 2; Elisabeth Gawthrop, *The Color of Coronavirus: Covid-19 Deaths by Race and Ethnicity in the U.S.*, APM RSCH. LAB (Sept. 14, 2022), <https://www.apmresearchlab.org/covid/deaths-by-race>.
16. *Archive of COVID-19 Vaccination Data Updates*, CTRS. FOR DISEASE CONTROL & PREVENTION (Sept. 6, 2022), <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/distributing/vaccination-data-archived-updates.html> (see April 2021).
17. *Demographic Characteristics of People Receiving COVID-19 Vaccinations in the United States*, CTRS. FOR DISEASE CONTROL & PREVENTION <https://covid.cdc.gov/covid-data-tracker/#vaccination-demographic> (last viewed Sept. 23, 2022).
18. CTRS. FOR DISEASE CONTROL & PREVENTION, COVID-19 PANDEMIC RESPONSE, LABORATORY DATA REPORTING: CARES ACT SECTION 18115 (2022) <https://www.cdc.gov/coronavirus/2019-ncov/downloads/lab/hhs-laboratory-reporting-guidance-508.pdf>.
19. ANNIE E. CASEY FOUND., *supra* note 6.
20. TEACHING FOR DIVERSITY AND SOCIAL JUSTICE: A SOURCEBOOK, *supra* note 7.
21. Multiple reasons have been cited for the lack of data, including: (i) lack of adequate and consistent race and ethnicity data collection standards; (ii) outdated public health data systems; (iii) concern around collecting this information at the point of care (i.e., sensitive and potentially invasive); (iv) uncertainty about what is legally allowable; (v) concern about use and disclosure of information; and (vi) in some cases, failure to actually request the information. NAT’L NETWORK OF PUB. HEALTH INSTS., CHALLENGES AND OPPORTUNITIES FOR STRENGTHENING THE US PUBLIC HEALTH INFRASTRUCTURE: FINDINGS FROM THE SCAN OF THE LITERATURE (May 2021) <https://nnphi.org/wp-content/uploads/2021/06/NNPHI-E2A-Kresge-Report-Web.pdf>.
22. RUBIN ET AL., *supra* note 3.
23. Jen’nan Ghazal Read et al., *Disaggregating Heterogeneity among Non-Hispanic Whites: Evidence and Implications for U.S. Racial/Ethnic Health Disparities*, 40 *POPULATION RSCH. AND POL’Y REV.* 9 (2021).
24. Irina B. Grafova & Olga F. Jarrín, *Beyond Black and White: Mapping Misclassification of Medicare Beneficiaries Race and Ethnicity*, 78 *MED. CARE RSCH. AND REV.* 616 (2021).
25. Am. Med. Ass’n Staff News Writer, *Why race, ethnicity and language data is crucial to quality care*, AM. MED. ASS’N (Mar. 23, 2015), <https://www.ama-assn.org/delivering-care/patient-support-advocacy/why-race-ethnicity-and-language-data-crucial-quality-care>.
26. Am. Pub. Health Ass’n, *Analysis: Declarations of Racism as a Public Health Crisis*, ADVANCING RACIAL EQUITY, (2021), [https://www.apha.org/-/media/Files/PDF/topics/racism/Racism\\_Declarations\\_Analysis.ashx](https://www.apha.org/-/media/Files/PDF/topics/racism/Racism_Declarations_Analysis.ashx).
27. P. Braveman, *Health Equity: Everyone Counts – The Need for Disaggregated Data on Marginalized or Excluded Racial/Ethnic Groups*, ROBERT WOOD JOHNSON FOUND. (May 31, 2022), <https://www.rwjf.org/en/library/research/2022/05/health-equity--everyone-counts.html>.
28. NAT’L NETWORK OF PUB. HEALTH INSTS., *supra* note 21.
29. NAT’L NETWORK OF PUB. HEALTH INSTS., *supra* note 21.
30. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, ADDRESSING GAPS IN PUBLIC HEALTH REPORTING OF RACE AND ETHNICITY DATA FOR COVID-19: FINDINGS AND RECOMMENDATIONS AMONG 45 STATE AND LOCAL HEALTH DEPARTMENT, 8-9 (2022).
31. *Id.* at 9.

32. The constitutionality of the collection of public health data was put to the test in a case – *Whalen v. Roe* – involving the New York Controlled Substances Act of 1972. That law required New York physicians to include on prescriptions for certain controlled substances the name, address and age of the patient, and the names of the physician and dispensing pharmacy. *Whalen v. Roe*, 429 U.S. 589, 593 (1977). The prescription was to be issued in triplicate with one copy going to the New York State Department of Health. *Id.* Opponents of the law argued the actions of the state in collecting the data amounted to an invasion of a constitutionally protected “zone of privacy.” *Id.* at 599. The United States Supreme Court disagreed, holding the collection of personal information is often necessary to protect public health and is constitutional, stating “disclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice.” *Id.* at 602.
33. Through the various experts with whom we consulted, we consistently heard that data reporters, such as healthcare providers and laboratories, often fail to report race and ethnicity data. This is true even where law or rule explicitly requires reporting of race and ethnicity data and where legal penalties exist for failure to report. Failure to report occurs for a variety of reasons. See *supra* § 3.
34. For example, CSTE found that race and ethnicity in COVID-19 disease surveillance data was completed between 65–74% of the time. Race and ethnicity in laboratory data was only 29% complete. For COVID-19 vaccine administration data, race and ethnicity were completed 62% of the time. See COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30, at 10.
35. See, e.g., *Medical Encyclopedia: Reportable Diseases*, MEDLINEPLUS, <https://medlineplus.gov/ency/article/001929.htm> (last visited June 7, 2022); *National Notifiable Disease Surveillance System*, CTRS. FOR DISEASE CONTROL & PREVENTION, <https://www.cdc.gov/nndss/index.html> (last visited June 7, 2022).
36. CAL. CODE REGS. tit. 17 § 2500(d)(1). Because California collects ethnicity data, it must by statute collect information about several specific Asian and Pacific Islander groups (beyond those specified in the 2011 HHS standards), the list of which will expand in July 2022. See CAL. GOV’T CODE §§ 8310.5, 8310.7 (West 2019). Per CAL. GOV’T CODE § 8310.9 (West 2019), the Health Department as of 2022 must also allow respondents to select more than one race or ethnicity when reports are made. In response to COVID-19, California’s legislature in 2020 mandated that the department also require information about sexual orientation and gender identity in disease reports. CAL. HEALTH & SAFETY CODE § 120255.
37. 10A N.C. ADMIN. CODE § 41A .017.
38. N.J. ADMIN. CODE § 8:57-1.6(c)(2).
39. MICH. ADMIN. CODE § R. 325.173(11).
40. See, e.g., NEV. REV. STAT. § 441A.120; *id.* at § 441A.150(1).
41. See, e.g., MICH. COMP. LAWS § 333.2221 (authorizing the Michigan Department of Health and Human Services to protect the public health through organized programs to prevent and control disease, address environmental hazards, collect and utilize vital and health statistics, and make investigations and inquiries into a variety of general public health issues); *id.* at § 333.2226 (authorizing the Michigan Department of Health and Human Services to engage in research, exercise authority, and promulgate rules to safeguard the public’s health).
42. Daniel W. Martin et al., *Immunization information systems: a decade of progress in law and policy*, 21(3) J. OF PUB. HEALTH MGMT. AND PRAC., 296. (2015). <https://doi.org/10.1097/PHH.0000000000000040>. (In comparison, 68% of jurisdictions relied on law specifically authorizing an immunization registry, while 11% operated their immunization registries on the basis of immunization information sharing laws, and 2% had done so relying on laws permitting exchange of general health information.).
43. *Id.*
44. *Behavioral Risk Factor Surveillance Systems*, CTRS. FOR DISEASE CONTROL & PREVENTION (Aug. 29, 2022), <https://www.cdc.gov/brfss/index.html>
45. Indeed, during a public health emergency, one of HHS’ specific roles is to promote uniformity in the data used by the states’ health agencies. 42 U.S.C. § 300hh-10.
46. *COVID-19 Vaccination Data in the United States*, CTRS. FOR DISEASE CONTROL & PREVENTION (Apr. 29, 2022), <https://www.cdc.gov/coronavirus/2019-ncov/vaccines/distributing/demographics-vaccination-data.html>
47. *Id.*
48. The White House’s Office of Management and Budget (OMB) is charged with evaluating the effectiveness of government programs. *Office of Management and Budget*, THE WHITE HOUSE, <https://www.whitehouse.gov/omb/> (last visited Feb. 15, 2022).
49. Off. of the Assistant Sec’y for Plan. and Evaluation, *U.S Department of Health and Human Services Implementation Guidance on Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*, (2011) <https://aspe.hhs.gov/sites/default/files/private/pdf/76331/index.pdf>.
50. *About the Topic of Race*, U.S. CENSUS BUREAU (Mar. 1, 2022) <https://www.census.gov/topics/population/race/about.html>.
51. Off. of Mgmt. and Budget, *Federal Register Notice- Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*, THE WHITE HOUSE OF PRESIDENT BARACK OBAMA (October 30, 1997), [https://obamawhitehouse.archives.gov/omb/fedreg\\_1997standards](https://obamawhitehouse.archives.gov/omb/fedreg_1997standards).
52. Off. of the Assistant Sec’y for Plan. and Evaluation, *supra* note 49. Section 4302 of the Patient Protection and Affordable Care Act (ACA) sets data collection standards for any federally facilitated health care or public health program, activity, or survey (including Medicare and Medicaid) to inform areas of health disparities. 42 U.S.C. § 300kk.
53. *Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity*, 62 Fed. Reg. 58782, 58788 (“The standards have been developed to provide a common language for uniformity and comparability in the collection and use of data on race and ethnicity by Federal agencies.”); *CMS Technical Instructions: Reporting Race and Ethnicity in the T-MSIS Eligible File*, MEDICAID, <https://www.medicaid.gov/medicaid/data-and-systems/macbis/tmsis/tmsis-blog/109701> (“The Patient Protection and Affordable Care Act requires federal data collection efforts for health care to follow the 1997 OMB standards, although states can opt for more granular reporting as long as the categories reported can be rolled up to the OMB standards.”); Patient Protection and Affordable Care Act, Pub. L. No. 111–148, 124 Stat. 119 (2010).
54. *CMS Technical Instructions: Reporting Race and Ethnicity in the T-MSIS Eligible File*, *supra* note 53 (“The Patient Protection and Affordable Care Act requires federal data collection efforts for health care to follow the 1997 OMB standards, although states can opt for more granular reporting as long as the categories reported can be rolled up to the OMB standards.”); Patient Protection and Affordable Care Act, Pub. L. No. 111–148, 124 Stat. 119 (2010).
55. On the day of his inauguration, President Biden signed Executive Order 13985 entitled “Advancing Racial Equity and Support for Underserved Communities Through the Federal Government.” Among other things, EO 13985 created an Equitable Data Working Group to identify inadequacies in existing Federal data collection policies and to expand and refine the data available to the Federal Government to measure equality. Exec. Order No. 13985, 86 Fed. Reg. 7,099 January 25, 2021.
56. Off. of Mgmt. and Budget, *supra* note 51.
57. Neda Maghbouleh, *From White to What? MENA and Iranian American Non-white Reflected Race*, 43 ETHNIC AND RACIAL STUD. 613 (2020); NEDA MAGHBOULEH, *THE LIMITS OF WHITENESS: IRANIAN-AMERICANS AND THE EVERYDAY POLITICS OF RACE* (2017).
58. Christian Edlagan & Kavya Vaghul, *How data disaggregation matters for Asian Americans and Pacific Islanders*, WASH. CTR. FOR EQUITABLE GROWTH (Dec. 14, 2016), <https://equitablegrowth.org/how-data-disaggregation-matters-for-asian-americans-and-pacific-islanders/>.
59. RUBIN ET AL., *supra* note 3.

60. See, e.g., Melissa R. Herman, *Do You See What I Am? How Observers' Backgrounds Affect Their Perceptions of Multiracial Faces*, 73 SOC. PSYCH. Q., 58 (2010); Aliya Saperstein, *Double-Checking the Race Box: Examining Inconsistency between Survey Measures of Observed and Self-Reported Race*, 85 SOC. FORCES, 57 (2006); Aliya Saperstein, *Different Measures, Different Mechanisms: A New Perspective on Racial Disparities in Health Care*, 27 SOC. SOURCES OF DISPARITIES IN HEALTH AND HEALTH CARE & LINKAGES TO POL'Y, POPULATION CONCERNS & PROVIDERS OF CARE (RSCH. IN THE SOCIO. OF HEALTH CARE) 21 (2009).
61. Santa Clara Pueblo v. Martinez, 436 U.S. 49, 55, n.32 (1978). For selected Tribal membership laws, see, CONSTIT. OF THE CHEROKEE NATION OF OKLAHOMA art III, (1975), <https://attorneygeneral.chokeee.org/media/5upcrg3j/word-searchable-full-code.pdf>; MUSKOGEE (CREEK) NATION CODE ANN. tit. 7 (1985), <http://www.creeksupremecourt.com/wp-content/uploads/title7.pdf>; "Membership," CONSTIT. OF THE KENAITZE INDIAN TRIBE art. 4 (1971), <https://www.kenaitze.org/wp-content/uploads/Amended-and-Approved-Constitution.pdf>; NAVAJO NATION CODE ANN. tit. 1 ch. 7., <https://epub.sub.uni-hamburg.de/epub/volltexte/2009/1893/pdf/nnc.pdf>. For selected Tribal enrollment policies, see *Tribal Registration*, CHEROKEE NATION, <https://www.cherokee.org/all-services/tribal-registration/>; *Enrollment*, POKAGON BAND OF POTAWATOMI, <https://www.pokagonband-nsn.gov/citizens/enrollment>; *Census Tribal Enrollment Office*, PUEBLO OF ISLETA <https://www.isletapueblo.com/census-department/>; *Enrollment Information – Native Village of Eklutna*, NATIVE VILLAGE OF EKLUTNA TRIBAL GOVERNMENT, <http://eklutna-nsn.gov/departments/enrollment-information/> (last visited Dec. 20, 2021).
62. Morton v. Mancari, 417 U.S. 535, 553-55 (1974); Moe v. Confederated Salish and Kootenai Tribes, 425 U.S. 463, 480 (1976).
63. See, COHEN'S HANDBOOK OF FEDERAL INDIAN LAW § 3.03 (Nell Jessup Newton ed., 2021).
64. MALIA VILLEGAS ET AL., *DISAGGREGATING AMERICAN INDIAN & ALASKA NATIVE DATA: A REVIEW OF LITERATURE* (2016), [https://www.ncai.org/DataDisaggregationAIAN-report\\_5\\_2018.pdf](https://www.ncai.org/DataDisaggregationAIAN-report_5_2018.pdf).
65. *About the Topic of Race*, *supra* note 50.
66. D'Vera Cohn, *American Indian and white, but not 'multiracial'*, PEW RESEARCH CENTER (June 11, 2015), <https://www.pewresearch.org/fact-tank/2015/06/11/american-indian-and-white-but-not-multiracial/>.
67. TRIBAL EPIDEMIOLOGY CTRS., *BEST PRACTICES IN AMERICAN INDIAN & ALASKA NATIVE PUBLIC HEALTH* (2013), [http://itcaonline.com/wp-content/uploads/2014/03/TEC\\_Best\\_Practices\\_Book\\_2013.pdf](http://itcaonline.com/wp-content/uploads/2014/03/TEC_Best_Practices_Book_2013.pdf).
68. D'Vera Cohn, *supra* note 66..
69. TRIBAL EPIDEMIOLOGY CTRS., *supra* note 67.
70. Nancy López & Vivian L. Gadsden, *Health Inequities, Social Determinants, and Intersectionality*, NAM PERSPECTIVES (Dec. 5, 2016), <https://doi.org/10.31478/201612a>.
71. *Id.*
72. Karin Orvis, *Reviewing and Revising Standards for Maintaining, Collecting, and Presenting Federal Data on Race and Ethnicity*, THE WHITE HOUSE (June 15, 2022), <https://www.whitehouse.gov/omb/briefing-room/2022/06/15/reviewing-and-revising-standards-for-maintaining-collecting-and-presenting-federal-data-on-race-and-ethnicity/>.
73. STEPHEN L. PEVAR, *THE RIGHTS OF INDIANS AND TRIBES 1–2* (4th ed. 2012); *Frequently Asked Questions*, BUREAU OF INDIAN AFFS., U.S. DEP'T OF THE INTERIOR, <https://www.bia.gov/frequently-asked-questions> (last visited Dec. 6, 2021).
74. *Indian Entities Recognized by and Eligible to Receive Services from the United States Bureau of Indian Affairs*, 86 Fed. Reg. 7554 (Bureau of Indian Affs. Jan. 29, 2021).
75. STEPHEN L. PEVAR, *supra* note 73 at 81-82.
76. Aila Hoss, *A Framework for Tribal Public Health Law*, 20 NEV. L.J. 113, 119–20 (2019).
77. ROXANNE DUNBAR-ORTIZ, *AN INDIGENOUS PEOPLES' HISTORY OF THE UNITED STATES 39–42*, 46 (2014).
78. See Hoss, *supra* note 4.
79. Alana Knudson et al., *A Profile of Tribal Health Departments*, 18 WALSH CTR. FOR RURAL HEALTH ANALYSIS RSCH. BRIEF 1, 3–4 (2012), [http://www.norc.org/PDFs/Walsh%20Center/Research%20Briefs/Research%20Brief\\_W18\\_KnudsonA\\_Profile\\_2012.pdf](http://www.norc.org/PDFs/Walsh%20Center/Research%20Briefs/Research%20Brief_W18_KnudsonA_Profile_2012.pdf).
80. CTRS. FOR DISEASE CONTROL & PREVENTION, *PUBLIC HEALTH SURVEILLANCE: PREPARING FOR THE FUTURE* (2018), <https://www.cdc.gov/surveillance/pdfs/Surveillance-Series-Bookleth.pdf>.
81. *Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access*, U.S. GOV'T ACCOUNTABILITY OFF. (Mar. 4, 2022) <https://www.gao.gov/products/gao-22-104698>.
82. *Id.*
83. Pam Greenberg, *Privacy Protections in State Constitutions*, NAT'L CONF. OF STATE LEGISLATURES (Jan. 3, 2022), <https://www.ncsl.org/research/telecommunications-and-information-technology/privacy-protections-in-state-constitutions.aspx>.
84. See, e.g., Fla. Const. art. I, § 23; Haw. Const. art. I, § 7; Ill. Const. art. I, § 6; La. Const. art. I, § 5; S.C. Const. art I, § 10.
85. See, e.g., Ill. Const. art. I, § 6.
86. Haw. Const. art. I, § 6; Mont. Const. art. II, § 10.
87. See, e.g., 5 U.S.C.A. § 552a; 7 C.F.R. § 246.26(d)(4); 42 C.F.R. § 2.31; 45 C.F.R. § 164.508.
88. See, e.g., 42 C.F.R. § 2.52; 45 C.F.R. § 164.512(i).
89. See, e.g., 42 C.F.R. Subpart E; 45 C.F.R. § 164.512(e).
90. See, e.g., 7 C.F.R. § 246.26; 45 C.F.R. § 164.512(b)(1)(ii).
91. See, e.g., 45 C.F.R. § 164.512(b).
92. See, e.g., Neb. Rev. Stat. § 71-503.01(3) which allows de-identified data to be published and reported.
93. N.C. Gen. Stat. § 130a–143. See also Nev. Rev. Stat. § 441A-220(2) (disclosure can be made for statistical purposes "provided that the identity is not discernible from the information disclosed.").
94. CAL. CODE REGS. tit. 17 § 2502(f)(3).
95. See, e.g., Ill. Admin. Code tit. 77 § 690.200 ("Identifiable data may be released to the extent necessary for the treatment, control, investigation or prevention of diseases and conditions dangerous to the public health"); Neb. Stat. Ann. § 71-503.01(2); N.Y.C. Health Code § 11.11.
96. N.J. Admin. Code § 8:57-1.14.
97. Law expires when NJ state of emergency ceases. S2357, 2020 Sen., (N.J. 2020).
98. Pam Greenberg, *2022 Consumer Privacy Legislation*, NAT'L CONF. OF STATE LEGISLATURES (June 10, 2022), <https://www.ncsl.org/research/telecommunications-and-information-technology/2022-consumer-privacy-legislation.aspx>.



99. *Id.*
100. Although these particular five statutes contain definitions of de-identification that are harmonized with the HIPAA standard for health data and, in addition, contain broad exemptions for clinical and public health data, this area of law is rapidly evolving. Public health officials should carefully review any newly enacted state and federal laws to analyze their impact on public health reporting issues.
101. Soc. Sec. Act § 1902 (a)(7); 45 C.F.R. § 95.621.
102. Applies only to education records; applies protections to individuals; applies to educational agencies and institutions funded by the federal government.
103. Applies only to certain substance use disorder records; applies protections to individual; applies to federally assisted substance use disorder programs.
104. Applies to broad category of data; applies protections to individuals and establishments; applies to CDC projects.
105. Applies to broad category of data; applies protections to individuals; applies to federal agencies.
106. Applies only to WIC data; applies protections to individuals; applies to WIC programs.
107. Other state or federal laws may limit the information that can be disclosed to public health agencies and need to be analyzed in addition to HIPAA. For example, state law often protects HIV/AIDS and behavioral health data. These laws sometimes include exceptions to allow sharing with public health agencies. Federal rules protecting the confidentiality of certain substance use treatment information does not contain an exception for routine public health needs. See 42 C.F.R. § 2. The Family Educational Rights and Privacy Act (FERPA) protects education records, which may contain health information such as vaccination data. 20 U.S.C. § 1232g; 34 C.F.R. § 99. FERPA does not include an exemption for public health reporting, although it does allow disclosure of identifiable student records in connection with a health or safety emergency. 34 C.F.R. § 99.31(a)(10).
108. *Covered Entities and Business Associates*, U.S. DEP'T OF HEALTH & HUM. SERVS. (June 16, 2017), <https://www.hhs.gov/hipaa/for-professionals/covered-entities/index.html>.
109. 45 C.F.R. § 160.103.
110. *Id.* at § 164.502.
111. *Id.* at § 164.306.
112. *Id.* at § 164.512(b)(2).
113. Cal. Health & Safety Code § 120440(c).
114. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30, at 5.
115. The City of New York has its own registry of vital statistics. Deaths and births occurring in the City are reported to and recorded by the New York City Department of Health and Mental Hygiene.
116. N.Y. PUB. HEALTH LAW art. 21 tit. 6 § 2168(4)(a).
117. *Id.* at § 2168(4)(b).
118. See CTRS. FOR DISEASE CONTROL & PREVENTION, U.S. STANDARD CERTIFICATE OF DEATH (2003), <https://www.cdc.gov/nchs/data/dvs/death11-03final-acc.pdf>.
119. Colleen Healy Boufides et al., *FAQ: COVID-19 and Health Data – Responding to Public Health*, NETWORK FOR PUB. HEALTH. L. (June 22, 2020), <https://www.networkforphl.org/resources/faqs-covid-19-and-health-data-privacy/#reporting-to-public-health>.
120. *Id.*
121. US Certificate of Death Racial Categories include: White; Black or African American; American Indian of Alaska Native; Asian Indian; Chinese; Filipino; Japanese; Korean; Vietnamese; Other Asian (specify); Native Hawaiian; Guamanian or Chamorro; Samoan; Other Pacific Islander (specify); Other (specify). US Certificate of Death Ethnicity Categories include: No, not Spanish/Hispanic/Latino; Yes, Mexican, Mexican American, Chicano; Yes, Puerto Rican; Yes, Cuban; Yes, other Spanish/Hispanic/Latino (specify). CTRS. FOR DISEASE CONTROL & PREVENTION, *supra* note 118.
122. The fact of death is often not confidential. However, the U.S. Standard Certificate of Death collects additional information, such as cause of death and identifying information on the decedent's next of kin. State laws differ in the amount of information from the death certificate that may be disclosed. Arizona is an example of a state that broadly protects death information, specifically exempting it from its records access laws. See *Ball v. Arizona Dep't of Health Servs.*, No. 1 CA-CV 21-0134, 2021 WL 6121852 (Ariz. Ct. App. Dec. 28, 2021) (author not entitled to records related to COVID-19 death information on agency's dashboard because exempted). Ohio is an example of a state that considers death information to be protected health information. See *WCPO-TV v. Ohio Dep't of Health*, 2022-Ohio-1864, 189 N.E.3d 1287 (although death information is confidential, State failed to show that release of records related to COVID-19 deaths would pose risk of re-identification).
123. See, e.g., MICH. COMP. LAWS §§ 333.2883, 333.2888 (allowing Michigan's Registrar to release data and share information with researchers); Nev. Rev. Stat. § 440.170(3)(A) (allowing Nevada's Registrar to share such information).
124. See, e.g., OHIO ADMIN. CODE § 3701-5-12(A).
125. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30 at 14, tbl.1 (only 4% identified the law as a barrier to collection).
126. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30 at 14, tbl.1.
127. See *supra* Subsection 3.B.
128. 45 C.F.R. § 164.508; see also, *supra* § 2.
129. 45 C.F.R. § 164.512(b).
130. Tribal Epidemiology Centers are also defined as public health authorities for the purposes of HIPAA. *Id.* at § 164.501.
131. *Id.* at § 164.512(b).
132. The minimum necessary rule refers to HIPAA's requirement that a covered entity or business associate – when using or disclosing PHI or when requesting PHI – must make reasonable efforts to limit protected health information to the minimum necessary to accomplish the intended purpose of the use, disclosure, or request. See *Id.* at §§ 164.502(b), 164.514(d); see also *Health Information Privacy – Minimum Necessary Requirement*, U.S. DEP'T OF HEALTH & HUM. SERVS. (Apr 4, 2003), <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/minimum-necessary-requirement/index.html> (last visited October 21, 2022).
133. 45 C.F.R. § 164.514(d)(3)(iii)(A).
134. *Id.* at § 164.512(a).
135. *Id.* at § 164.502(b)(2).

136. Other state or federal laws may limit the information that can be disclosed to public health agencies and need to be analyzed in addition to HIPAA. For example, state law often protects HIV/AIDS and behavioral health data. These laws sometimes include exceptions to allow sharing with public health agencies. Federal rules protecting the confidentiality of certain substance use treatment information does not contain an exception for routine public health needs. See 42 C.F.R. § 2. The Family Educational Rights and Privacy Act (FERPA) protects education records, which may contain health information such as vaccination data. 20 U.S.C. § 1232g; 34 C.F.R. § 99. FERPA does not include an exemption for public health reporting, although it does allow disclosure of identifiable student records in connection with a health or safety emergency. 34 C.F.R. § 99.31(a)(10).
137. Mich. Dep't of Health & Hum. Servs. Memorandum Michigan's System of Public Health and Disease Investigations and Surveillance: COVID-19 Update (Sept. 22, 2020), [https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder4/Folder13/Folder3/Folder113/Folder2/Folder213/Folder1/Folder313/Disclosure\\_of\\_PHI\\_for\\_Disease\\_prevention\\_-\\_COVID\\_update\\_-\\_Final.pdf?rev=726a5c3c820b4288b1da212c076939bd](https://www.michigan.gov/-/media/Project/Websites/mdhhs/Folder4/Folder13/Folder3/Folder113/Folder2/Folder213/Folder1/Folder313/Disclosure_of_PHI_for_Disease_prevention_-_COVID_update_-_Final.pdf?rev=726a5c3c820b4288b1da212c076939bd); Arapahoe Cnty. Gov't Off. of the Cnty. Att'y Memorandum HIPAA & Public Health Emergencies (Feb. 28, 2020), <http://ccionline.org/wp-content/uploads/2020/03/Arapahoe-County-Memo-re-HIPAA-Public-Health-Emergencies.pdf>; COLO. DEP'T OF PUB. HEALTH & ENV'T, HIPAA AND PRIVACY FACT SHEET (Feb. 2020) [https://docs.google.com/document/d/1u8WfS9aKePZRJV9\\_tGlsGuZjB7dMDSShRkhwFCjrWwv/](https://docs.google.com/document/d/1u8WfS9aKePZRJV9_tGlsGuZjB7dMDSShRkhwFCjrWwv/) (last visited Oct. 21, 2022).
138. 42 U.S.C. § 300jj-52 (West).
139. *Id.*
140. *Id.*
141. 21st Century Cures Act: Interoperability, Information Blocking, and the ONC Health IT Certification Program, 85 Fed. Reg. 25642 (May 1, 2020) (to be codified at 45 C.F.R. pts. 170, 171).
142. 45 C.F.R. § 171.101.
143. See OFF. OF THE NAT'L COORDINATOR FOR HEALTH INFO. TECH., CURES ACT FINAL RULE: INFORMATION BLOCKING EXCEPTIONS, <https://www.healthit.gov/sites/default/files/2022-07/InformationBlockingExceptions.pdf> (fact sheet on exemptions, e.g., harm prevention, privacy, security, infeasibility, health IT performance, content and manner exceptions).
144. ONC's guidance provided that "[w]here a law requires actors to submit EHI to public health authorities, an actor's failure to submit EHI to public health authorities could be considered an interference under the information blocking regulations. For example, many states legally require reporting of certain diseases and conditions to detect outbreaks and reduce the spread of disease. Should an actor that is required to comply with such a law fail to report, the failure could be an interference with access, exchange, or use of EHI under the information blocking regulations." *Would not complying with another law implicate the information blocking regulations?*, HEALTHIT.GOV (July 20, 2022) <https://www.healthit.gov/faq/would-not-complying-another-law-implicate-information-blocking-regulations>.
145. The Department of Health and Human Services (HHS) Office of Inspector General (OIG) is authorized to investigate claims of information blocking. 42 U.S.C. § 300jj-52. If the OIG determines information blocking has occurred, it can apply civil money penalties in the case of information blocking by health information technology developers of certified health information technology, and health information exchanges and networks, and it can refer health care providers to other federal agencies for appropriate disincentives under applicable law. *Id.*; 45 C.F.R. pt. 171.
146. OR. HEALTH AUTH. & OR. DEP'T OF HUM. SERVS., RACE, ETHNICITY, LANGUAGE AND DISABILITY (REALD) DATA: HOUSE BILL 2134 BASELINE ASSESSMENT (2014), [https://www.oregon.gov/oha/OEI/REALD%20Documents/2014-Baseline-Assessment-of-the-Race-Ethnicity-Language-and-Disability-\(REALD\)-Data-Collection-within-DHS-and-OHA.pdf](https://www.oregon.gov/oha/OEI/REALD%20Documents/2014-Baseline-Assessment-of-the-Race-Ethnicity-Language-and-Disability-(REALD)-Data-Collection-within-DHS-and-OHA.pdf).
147. Or. Rev. Stat. §§ 413.161, 413.042. "The REALD rules (Chapter 943, Division 70) implement the Race, Ethnicity, Language, and Disability Demographic Data Collection Standards mandated by House Bill 2134 (2013). The Oregon Health Authority (OHA) has revised these rules and Oregon Disease Reporting rules to implement sections 40 through 43 of House Bill 4212 (2020 1st Special Session). The bill requires OHA to establish rules requiring collection and reporting of REALD information for COVID-19 cases reported to OHA." *REALD Rules and Policies*, OR. HEALTH AUTH., <https://www.oregon.gov/oha/OEI/Pages/REALD-Rules.aspx>.
148. The race and ethnicity categories Oregon currently uses include: American Indian; Alaska Native; Canadian Inuit, Metis or First Nation; Indigenous Mexican, Central American, or South American; Hispanic or Latino/a/x Mexican; Hispanic or Latino/a/x Central American; Hispanic or Latino/a/x South American; Other Hispanic or Latino/a/x; Asian Indian; Cambodian; Chinese; Communities of Myanmar; Filipino/a; Japanese; Korean; Laotian; Hmong; South Asian; Vietnamese; Other Asian; Chamoru (Chamorro); Communities of the Micronesian Region; Marshallese; Native Hawaiian; Samoan; Other Pacific Islander; African American; Afro-Caribbean; Ethiopian; Somali; Other African (Black); Other Black; Middle Eastern; North African; Western European; Slavic; Eastern European; Other White; and Other. OREGON HEALTH AUTHORITY EQUITY AND INCLUSION DIVISION, SCRIPT FOR COLLECTING REALD DATA OVER THE PHONE (Mar. 15, 2021) <https://www.oregon.gov/oha/OEI/REALD%20Documents/Phone-Script.pdf> (last visited June 22, 2022); OREGON ADMIN. R. 943-070-0030(2).
149. OR. ADMIN. R. 943-070-0030(1).
150. For example, "We are going to ask you a few questions about race and ethnicity starting with, 'Which of these categories do you think reflects your racial or ethnic identity?'" Off. of Equity and Inclusion, *Race, Ethnicity, Language, and Disability (REALD) Implementation*, OR. HEALTH AUTH., <https://www.oregon.gov/oha/OEI/Pages/REALD.aspx> (last visited June 22, 2022).
151. *Id.*
152. WASH. ADMIN. CODE § 246-101-011 (2002) (eff. Jan 1, 2023).
153. *Governors' Powers & Authority*, NAT'L GOVERNORS ASS'N, <https://www.nga.org/governors/powers-and-authority/> (last visited Aug. 15, 2022).
154. *Id.*; See also *What is an Executive Order?*, AMERICAN BAR ASSOCIATION, (Jan. 25, 2021) [https://www.americanbar.org/groups/public\\_education/publications/teaching-legal-docs/what-is-an-executive-order-/](https://www.americanbar.org/groups/public_education/publications/teaching-legal-docs/what-is-an-executive-order-/) (last visited Aug. 15, 2022) (describing executive powers at the federal level).
155. *Executive Orders Issued by Governors and State Agencies in Response to the Coronavirus (COVID-19) Pandemic, 2020*, BALLOTPEDIA, [https://ballotpedia.org/Executive\\_orders\\_issued\\_by\\_governors\\_and\\_state\\_agencies\\_in\\_response\\_to\\_the\\_coronavirus\\_\(COVID-19\)\\_pandemic,\\_2020](https://ballotpedia.org/Executive_orders_issued_by_governors_and_state_agencies_in_response_to_the_coronavirus_(COVID-19)_pandemic,_2020) (last visited Aug. 15, 2022) (cataloging the 2,065 executive and state agency orders issued between February and June 29, 2020). Michigan's Governor issued more than 190 executive orders or directives since the pandemic began in 2020. See *State Orders & Directives*, MICHIGAN.GOV – GOVERNOR GRETCHEN WHITMER, <https://www.michigan.gov/whitmer/news/state-orders-and-directives#z=1&q=COVID-19&e=0> (last visited Aug. 15, 2022) (search results for COVID-19 produce 192 results).
156. GOV. DOUGLAS A. DUCEY, EXECUTIVE ORDER 2021-07, ENHANCED SURVEILLANCE ADVISORY: MONITORING AND PREVENTING THE SPREAD OF COVID-19 (Arizona) [https://www.southtucsonaz.gov/sites/default/files/fileattachments/community/page/4288/governor\\_ducey\\_executive\\_order\\_2021-07\\_enhanced\\_surveillance\\_advisory\\_monitoring\\_and\\_preventing\\_the\\_spread\\_of\\_covid-19.pdf](https://www.southtucsonaz.gov/sites/default/files/fileattachments/community/page/4288/governor_ducey_executive_order_2021-07_enhanced_surveillance_advisory_monitoring_and_preventing_the_spread_of_covid-19.pdf).
157. COLO. DEP'T OF PUB. HEALTH AND ENV'T, THIRD AMENDED PUBLIC HEALTH ORDER 21-01, VACCINE ACCESS AND DATA REPORTING FOR COVID-19 (Nov. 14, 2021) <https://drive.google.com/file/d/1a1Ynu6xRR3u4ZfmoJHpOgJg7QQPjBmRO/view>.
158. ORD. OF THE COMM'R OF HEALTH OF THE CITY OF CHI., NO. 2020-4 – SECOND AMENDED AND RE-ISSUED MEDICAL DATA-SHARING REQUIREMENTS (Feb. 24, 2022) <https://www.chicago.gov/content/dam/city/sites/covid/health-orders/2022/2020-4%20reissued%2002.2022.pdf>.

159. CITY AND COUNTY OF S.F. DEPARTMENT OF PUBLIC HEALTH, ORD. OF THE HEALTH OFF. No. C19-16, ORDER OF THE HEALTH OFFICER OF THE CITY AND COUNTY OF SAN FRANCISCO REQUIRING HOSPITALS IN THE CITY AND COUNTY OF SAN FRANCISCO TO PROVIDE PATIENT DATA FOR INPATIENTS WITH SARS-COV-2 INFECTIONS FOR THE PURPOSE OF PUBLIC HEALTH PREVENTION AND RESPONSE EFFORTS (Dec. 11, 2020) <https://sf.gov/sites/default/files/2022-03/Order-C19-16-Hospitals-Data.pdf>; CAL. DEP'T OF PUB. HEALTH, COVID-19 CONFIDENTIAL MORBIDITY REPORT, <https://www.sfdcpc.org/wp-content/uploads/2020/04/CDPH-SFCOVID19-CMR-2022.03.28.pdf>.
160. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30, at 14, tbl.1. A significant percentage of respondents indicated that these barriers were issues for each of the data sets asked about. For example, patient hesitance ranged from 60%–72%; reporters failure to provide from 88%–96%; information system limitation from 36%–68%; insufficient guidance, requirements or standards for collection and coding from 36%–48%; and limited resources and staffing for health departments from 32%–54%. *Id.* Another report identified the following as barriers to the collection of race and ethnicity data: outdated data standards, lack of consistent collection of data, technological challenges (i.e., old data systems, lack of interoperability), financial and staff resources, and concern about asking patients to disclose their race and ethnicity. See GRANTMAKERS IN HEALTH & NAT'L COMM. FOR QUALITY ASSURANCE, FEDERAL ACTION IS NEEDED TO IMPROVE RACE AND ETHNICITY DATA IN HEALTH PROGRAMS 6 (Oct. 2021) <https://www.gih.org/wp-content/uploads/2021/10/GIH-Commonwealth-Fund-federal-data-report-part-1.pdf>.
161. 60–72% and 88–96% of respondents respectively reported that their health departments experienced these barriers. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30, at 13, tbl.1.
162. See NAIMA WONG CROAL ET AL., IDENTIFYING GOVERNMENTAL PUBLIC HEALTH SYSTEM BARRIERS AND FACILITATORS TO COMPLYING WITH AND EXPANDING RACE AND ETHNICITY DATA DISAGGREGATION STANDARDS 15–16 (Mar. 31, 2022); see also Discussion with UCLA Center for Health Policy Research (Jan. 11, 2022) (on file with author) (indicating that data collection barriers are logistical, resource, and technical in nature); Facilitated Discussion with Council for State and Territorial Epidemiologists public health law and health policy subcommittees (Feb. 11, 2022) (on file with author) [hereinafter CSTE Discussion]; Discussion with Association of State and Territorial Health Officials (Jan. 13, 2022) (on file with author).
163. See Naima T. Wong et al. Internal Report submitted to Robert Wood Johnson Foundation, Identifying Systems-level Barriers to Complying with and Expanding National Race & Ethnicity Data Disaggregation Standards, 4 (April 19, 2021) (on file with author). See also CROAL ET AL., *supra* note 162 at 14–16.
164. See CROAL ET AL., *supra* note 162 at 14; CSTE Discussion, *supra* note 162.
165. Even prior to the COVID-19 pandemic, 71% of hospitals stated they experienced challenges with public health reporting. Hannah Nelson, *Hospital Public Health Reporting Hiccups Common Before COVID-19*, EHR INTELLIGENCE, (Sept. 9, 2021) <https://ehrintelligence.com/news/hospital-public-health-reporting-hiccups-common-before-covid-19/>; see also CHELSEA RICHWINE ET AL., CHALLENGES TO PUBLIC HEALTH REPORTING EXPERIENCED BY NON-FEDERAL ACUTE CARE HOSPITALS, 2019 (Sept. 2021), <https://www.healthit.gov/sites/default/files/page/2021-09/Challenges-to-PH-Reporting.pdf>. Despite EHR technology supporting public health reporting, many providers do not use these capabilities due to cost, limited staffing, and lack of familiarity with how to send data. Molly Murray, *How Federal Rules Can Help Public Health Agencies Get the Data They Need*, Pew Charitable Trusts (Oct. 26, 2021), <https://www.pewtrusts.org/en/research-and-analysis/articles/2021/10/26/how-federal-rules-can-help-public-health-agencies-get-the-data-they-need> (last visited June 14, 2022).
166. See Naima T. Wong et al. Internal Report submitted to Robert Wood Johnson Foundation, *supra* note 163 at 3; see also CROAL ET AL., *supra* note 162 at 14. The authors acknowledge that some data sharing silos within health departments are due, at least in part, to varying confidentiality requirements for certain types of data, such as HIV. In these circumstances, data may be siloed out of legal necessity.
167. Lauren Weber et al., *Hollowed-Out Public Health System Faces More Cuts Amid Virus*, KHN (July 1, 2020), <https://khn.org/news/us-public-health-system-underfunded-under-threat-faces-more-cuts-amid-covid-pandemic/>. See CROAL ET AL., *supra* note 162 at 19–20.
168. See Naima T. Wong et al. Internal Report submitted to Robert Wood Johnson Foundation, *supra* note 163 at 6; See CROAL ET AL., *supra* note 162 at 19–20.
169. Note that the law is but one tool in the toolbox to address race and ethnicity data collection and quality issues. For example, legislation is not a standalone solution and, indeed, can be meaningless without action and enforcement to operationalize the law. See CROAL ET AL., *supra* note 162 at 32.
170. In this context, the term provider may include a health care provider, vaccine administrator, hospital, or laboratory.
171. See *supra* § 3.
172. See *supra* § 3.
173. We recognize that given the atmosphere during the COVID-19 pandemic and the attacks on public health authority, many state and local health departments may be hesitant to pursue new legislation or amend existing legislation. Administrative rulemaking can also be political, and health departments may likewise be hesitant to pursue or amend rules.
174. CSTE Discussion, *supra* note 162; Discussion with Association of State and Territorial Health Officials, *supra* note 162.
175. See *supra* § 3.
176. N.J. ADMIN. CODE § 8:57-1.15.
177. N.Y. PUB. HEALTH LAW § 12.
178. *Mandatory Reporting of Infectious Diseases by Clinicians*, 39 Morbidity and Mortality Wkly. Rep. (Ctrs. for Disease Control, 1989), <https://www.cdc.gov/mmwr/preview/mmwrhtml/00001665.htm>; Colleen Healy Boufides et al., *supra* note 119.
179. Provider outreach and education is preferred among health departments to explain legal requirements and encourage reporting of race and ethnicity data. COUNCIL FOR STATE AND TERRITORIAL EPIDEMIOLOGISTS, *supra* note 30 at 18, 21, 28–30 (2022); CSTE Discussion, *supra* note 162; Discussion with Association of State and Territorial Health Officials, *supra* note 162.
180. Mich. Dep't of Health & Hum. Servs. Memorandum Michigan's System of Public Health and Disease Investigations and Surveillance: COVID-19 Update, *supra* note 137; Arapahoe Cnty. Gov't Off. of the Cnty. Att'y Memorandum HIPAA & Public Health Emergencies, *supra* note 137; COLO. DEP'T OF PUB. HEALTH & ENV'T, *supra* note 137.
181. See *supra* § 3.
182. GRANTMAKERS IN HEALTH & NAT'L COMM. FOR QUALITY ASSURANCE, *supra* note 160 at 12–13; see also GRANTMAKERS IN HEALTH & NAT'L COMM. FOR QUALITY ASSURANCE, IMPROVING DATA ON RACE AND ETHNICITY: A ROADMAP TO MEASURE AND ADVANCE HEALTH EQUITY 18–22 (Dec. 2021) <https://www.gih.org/wp-content/uploads/2021/12/GIH-Commonwealth-Fund-federal-data-report-part-2.pdf>.
183. GRANTMAKERS IN HEALTH & NAT'L COMM. FOR QUALITY ASSURANCE, *supra* note 160 at 9.
184. 42 U.S.C. § 300kk (2010) (emphasis added).
185. See *supra* § 2.
186. Medicare Program; CY 2022 Payment Policies Under the Physician Fee Schedule and Other Changes to Part B Payment Policies; Medicare Shared Savings Program Requirements; Provider Enrollment Regulation Updates; and Provider and Supplier Prepayment and Post-Payment Medical Review Requirements, 86 Fed. Reg. 64,996 (Nov. 19, 2021) (to be codified at 42 C.F.R. pts. 403, 405, 410, 411, 414, 415, 423, 424, 425).

187. Molly Murray, *New Federal Policies Seek More Data for Public Health, Emphasize Health IT Safety*, PEW CHARITABLE TRUSTS (Nov. 15, 2021), <https://www.pewtrusts.org/en/research-and-analysis/articles/2021/11/15/new-federal-policies-seek-more-data-for-public-health-emphasize-health-it-safety> (last visited June 13, 2022); see also CTRS. FOR MEDICARE AND MEDICAID SERVS., MEDICARE PROMOTING INTEROPERABILITY PROGRAM FOR ELIGIBLE HOSPITALS AND CRITICAL ACCESS HOSPITALS: OBJECTIVES AND MEASURES FOR THE 2022 HER REPORTING PERIOD, <https://www.cms.gov/files/document/6-ipp-fy-2022-immunization-registry-reporting.pdf>, (last visited June 13, 2022).
188. Memo to All Medicare Advantage Organizations (MA), Prescription Drug Plan Sponsors (PDP), Program of All-Inclusive Care for the Elderly (PACE), and Demonstration Organizations, Model Individual Enrollment Request Form to Enroll in a Medicare Advantage Plan (MA) or a Medicare Prescription Drug Plan (Part D), and Advance Announcement of January 2023 Software Release – Addition of Race and Ethnicity Data Fields on Enrollment Transactions (July 5, 2022), <https://www.cms.gov/files/document/hpms-announcement-memo-race-and-ethnicity.pdf> (listing race and ethnicity fields that go beyond OMB's requirements but do not include categories like Middle Eastern or North African).
189. See CROAL ET AL., *supra* note 162 at 17.
190. Orvis, *supra* note 72.
191. CTRS. FOR DISEASE CONTROL & PREVENTION, COVID-19 PUBLIC HEALTH DATA MODERNIZATION (Nov. 18, 2020), [https://www.cste.org/resource/resmgr/data\\_health/covid-19-data-modernization-.pdf](https://www.cste.org/resource/resmgr/data_health/covid-19-data-modernization-.pdf) (last visited Aug. 7, 2022).
192. *Data Modernization Initiative: Why Sustainable Funding Matters*, CTRS. FOR DISEASE CONTROL & PREVENTION (Oct. 12, 2022), <https://www.cdc.gov/surveillance/surveillance-data-strategies/dmi-investments.html> (last visited Oct. 25, 2022).
193. *Id.*
194. CTRS. FOR DISEASE CONTROL & PREVENTION, *supra* note 191; CTRS. FOR DISEASE CONTROL & PREVENTION, *Public Health Surveillance and Data: What is the Data Modernization Initiative?*, <https://www.cdc.gov/surveillance/projects/dmi-initiative/index.html> (last visited Aug. 7, 2022). See CARES Act, tit. VIII, Stat. 555, <https://www.congress.gov/116/plaws/publ136/PLAW-116publ136.htm>.
195. CTRS. FOR DISEASE CONTROL & PREVENTION, *supra* note 192.
196. See DATA: ELEMENTAL TO HEALTH, MODERNIZE PUBLIC HEALTH DATA: A CALL TO CONGRESS, [https://cdn.ymaws.com/www.cste.org/resource/resmgr/data\\_health/DMI\\_Costs\\_One\\_Pager\\_FINAL\\_08.pdf](https://cdn.ymaws.com/www.cste.org/resource/resmgr/data_health/DMI_Costs_One_Pager_FINAL_08.pdf) (last visited Oct. 25, 2022) (estimating \$7.84B over five years); *Public Health Information and Technology Infrastructure Modernization Funding Report*, HEALTHCARE INFO. & MGMT. SYS. SOC'Y (Apr. 29, 2022), <https://www.himss.org/resources/public-health-information-and-technology-infrastructure-modernization-funding-report> (last visited Oct. 25, 2022) (estimating \$36.7B over ten years).
197. See, e.g., Freedom of Information Act (FOIA), 5 U.S.C. § 552.
198. Tyler Valeska, *Law clinic helps NYTimes win access to COVID-19 data on race*, CORNELL CHRONICLE (July 7, 2020), <https://news.cornell.edu/stories/2020/07/law-clinic-helps-nytimes-win-access-covid-19-data-race>.
199. *Id.*
200. Richard A. Oppel Jr. et al., *The Fullest Look Yet at the Racial Inequity of Coronavirus*, N.Y. TIMES (July 5, 2020), <https://www.nytimes.com/interactive/2020/07/05/us/coronavirus-latinos-african-americans-cdc-data.html>.
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202. Letter from Paula Yoon, ScD, MPH, Data, Analytics, and Modeling Task Force Lead, CDC COVID-19 Emergency Response, Div. Dir., Div. of Health Informatics and Surveillance, Center for Surveillance, Epidemiology and Laboratory Services, Ctrs. for Disease Control and Prevention to Council for State and Territorial Epidemiologists (Aug. 28, 2020) (on file with author).
203. Freedom of Information Act (FOIA), 5 U.S.C. § 552.
204. *Open Government Guide*, REPORTERS COMMITTEE FOR FREEDOM OF THE PRESS, <https://www.rcfp.org/open-government-guide/>.
205. See, e.g., *King v. Cook Cnty. Health and Hosp. Sys.*, 2020 IL App (1st) 190925, ¶ 15.
206. Jessica Terkovich & Aryeh Frank, *Constitutionalizing access: How courts weigh state constitutional claims in open-government litigation*, 3 J. OF CIVIC INFO. (2021).
207. *Voice of San Diego v. Superior Ct. of San Diego Cnty.*, 66 Cal. App. 5th 669, 682 (2021)
208. The examples provided here are for illustrative purposes. The freedom of information laws in each of the states include other exemptions not listed here.
209. OHIO REV. CODE § 149.43(A)(1). Other laws that prohibit release of information may include privacy laws.
210. NEB. REV. STAT. § 84-712.05(2).
211. TENN. CODE ANN. § 10-7-504(1).
212. Public Officers Law, N.Y. CONS. LAWS § 87(2)(b). See also 5 ILL. COMP. STAT. 140/1.
213. 5 ILL. COMP. STAT. 140/7(1)(a)-(b).
214. *Id.* at 140/7(1)(c).
215. *Voice of San Diego v. Superior Ct. of San Diego Cnty.*, 66 Cal. App. 5th 669, 682 (2021).
216. See, e.g., Illinois Freedom of Information Act, 5 ILL. COMP. STAT. 140/9.
217. Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82462, 82482 (Dec. 28, 2000).
218. *King v. Cook Cnty. Health and Hosp. Sys.*, 2020 IL App (1st) 190925, ¶ 46.
219. Latanya Sweeney et al., *Re-identification risks in HIPAA Safe Harbor data: A study of data from one environmental health study*, TECH. SCI. 2017, (2017).
220. 45 C.F.R. §164.514.
221. U.S. DEP'T OF HEALTH & HUM. SERVS., GUIDANCE REGARDING METHODS FOR DE-IDENTIFICATION OF PROTECTED HEALTH INFORMATION IN ACCORDANCE WITH THE HEALTH INSURANCE PORTABILITY AND ACCOUNTABILITY ACT (HIPAA) PRIVACY RULE (Nov. 26, 2012), [https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/coveredentities/De-identification/hhs\\_deid\\_guidance.pdf](https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/coveredentities/De-identification/hhs_deid_guidance.pdf).
222. 45 C.F.R. § 164.514(b)(1).
223. *Id.* at § 164.514(b)(2).
224. Standards for Privacy of Individually Identifiable Health Information, 65 Fed. Reg. 82462, 82543 (Dec. 28, 2000).
225. *Id.*
226. 45 C.F.R. § 160.514(2)(b).

227. The list of 18 identifiers has been edited for length. For the unedited list, see *id.* at § 164.514(b). The Privacy Rule also allows for creation of a limited data set, which excludes most identifiers but may include, e.g., town or City, state and ZIP code and elements of dates. *Id.* at § 164.514(e).
228. See, e.g., Mayor's Press Off., *Mayor Lightfoot and CDPH Release New Demographic Data Release to COVID-19 Revealing Significant Racial Health Inequities*, CHI. OFF. OF THE MAYOR (April 6, 2020), [https://www.chicago.gov/city/en/depts/mayor/press\\_room/press\\_releases/2020/april/COVID19RacialInequities.html](https://www.chicago.gov/city/en/depts/mayor/press_room/press_releases/2020/april/COVID19RacialInequities.html).
229. See, e.g., *Neighborhood Data Profiles*, NYC HEALTH, <https://www1.nyc.gov/site/doh/covid/covid-19-data-neighborhoods.page>; Latest Data, CHICAGO, <https://www.chicago.gov/city/en/sites/covid-19/home/covid-dashboard.html>.
230. OR. ADMIN. R. 943-070 et seq.
231. *Wisconsin Manufacturers and Commerce v. Evers*, 977 N.W.2d 374 (Wis. 2022).
232. *Id.* at 382.
233. *Id.* at 383.
234. GEORGE T. DUNCAN ET AL., *STATISTICAL CONFIDENTIALITY: PRINCIPLES AND PRACTICE* (2011).
235. See, e.g., ROBERT WOOD JOHNSON FOUND., *CHARTING A COURSE FOR AN EQUITY-CENTERED DATA SYSTEM: RECOMMENDATIONS FROM THE NATIONAL COMMISSION TO TRANSFORM PUBLIC HEALTH DATA SYSTEMS* (October 2021). See also THE LEADERSHIP CONF., *INFORMATION NATION: THE NEED FOR IMPROVED FEDERAL CIVIL RIGHTS DATA COLLECTION* (April 2022), <https://civilrightsdocs.info/pdf/reports/Information-Nation-2022.pdf> (finding aggregated data hide inequities).
236. A VISION FOR EQUITABLE DATA: RECOMMENDATIONS FROM THE EQUITABLE DATA WORKING GROUP, *supra* note 8.
237. Daniel C. Barth-Jones, *Ethical Concerns, Conduct and Public Policy for Re-Identification and De-identification Practice: Part 3 (Re-Identification Symposium)*, BILL OF HEALTH (Oct. 2, 2013), <https://blog.petrieflom.law.harvard.edu/2013/10/02/ethical-concerns-conduct-and-public-policy-for-re-identification-and-de-identification-practice-part-3-re-identification-symposium/>.
238. See, e.g., New York Personal Privacy Protection Law, N.Y. CONS. LAWS §§ 91-99.
239. TENN. CODE ANN. § 63-2-101.
240. TEX. HEALTH & SAFETY CODE § 181.154.
241. NEB. REV. STAT. § 81-667.
242. 186 NEB. ADMIN. CODE, ch. 5 et seq.
243. 5 U.S.C. § 552a.
244. CAL. CIV. CODE § 1798 et seq.
245. N.Y. Pub. Off. Law § 96 (McKinney).
246. Chic. Open Data Exec. Order No. 2012-2 (2012), [https://www.chicago.gov/city/en/narr/foia/open\\_data\\_executiveorder.html](https://www.chicago.gov/city/en/narr/foia/open_data_executiveorder.html).
247. *Id.*
248. Making Open and Machine Readable the New Default for Government Information, 78 Fed. Reg. 28111 (May 14, 2003).
249. Exec. Order No. 13994, 86 Fed. Reg. 7,189 (Jan 26, 2021).
250. *Id.*
251. S2357, 2020 Sen., (N.J. 2020).
252. Pam Greenberg, *State Open Data Laws and Policies*, NAT'L CONF. OF STATE LEGISLATURES (Jan. 25, 2022) <https://www.ncsl.org/research/telecommunications-and-information-technology/state-open-data-laws-and-policies.aspx>.
253. *Id.*
254. *Open Government*, DATA.GOV, <https://data.gov/open-gov/>.
255. See, e.g., Patient Protection and Affordable Care Act, Pub. L. No. 111-148, § 4302, 124 Stat. 119 (2010); 42 U.S.C. § 300kk; Public Health and Welfare, Research & Investigations Generally, *id.* at § 241; Facilities and Capacities of the Centers for Disease Control and Prevention, *id.* at § 247d-4; Coordination of Preparedness for and Response to all-hazards Public Health Emergencies, *id.* at § 300hh-10; Data Supplied by the U.S. Department of Justice, Joint Resolution, Public L. No. 94-311, 90 Stat. 688.
256. 45 C.F.R. § 164.512(b).
257. *Id.* at § 164.512(b)(2).
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259. NETWORK FOR PUBLIC HEALTH L., *SUMMARY OF STATE LAWS THAT FACILITATE DATA SHARING AMONG STATE AGENCIES* (Oct. 22, 2019), <https://www.networkforphl.org/wp-content/uploads/2019/10/Summary-of-State-Laws-that-Facilitate-Data-Sharing-Among-State-Agencies-11-7-19.pdf>; <https://malegislature.gov/Laws/SessionLaws/Acts/2015/Chapter55>.
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262. Office of Gov. Brian P. Kemp, Exec. Order No. 11.20.20.01, <https://gov.georgia.gov/document/2020-executive-order/11202001>.
263. NAT'L ASS'N OF CNTY. & CITY HEALTH OFFS., 2019 NATIONAL PROFILE OF LOCAL HEALTH DEPARTMENTS [https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/NACCHO\\_2019\\_Profile\\_final.pdf](https://www.naccho.org/uploads/downloadable-resources/Programs/Public-Health-Infrastructure/NACCHO_2019_Profile_final.pdf).
264. *Id.*
265. *Id.*
266. 720 ILL. COMP. STAT. 570/318(d).
267. MUN. CODE OF CHI. § 2-112-110(a)(7).
268. CAL. DEP'T OF HEALTH CARE SERVS., *GUIDELINES AND INSTRUCTIONS FOR OPTIONAL LETTER OF SUPPORT FOR STATE DEPARTMENT OF HEALTH CARE PLAN MEDI-CAL MANAGED CARE PLAN PROCUREMENT*, <https://www.sandiegocounty.gov/content/dam/sdc/hhsa/programs/ssp/documents/CalAIM%20-%20MCO%20Letter%20of%20Support%20Instructions%207-13-21.pdf>.
269. Public Health Authority is defined within the HIPAA Privacy Rule to mean "an agency or authority of the United States, a State, a territory, a political subdivision of a State or territory, or an Indian tribe, or a person or entity acting under a grant of authority from or contract with such public agency, including the employees or agents of such public agency or its contractors or persons or entities to whom it has granted authority, that is responsible for public health matters as part of its official mandate." 45 C.F.R. § 164.501.

270. See Hoss, *supra* note 4. Udall, Murray, Pallone, Grijalva, Gallego Raise Concerns about Tribes Being Denied Access to Critical Federal COVID-19 Data, *supra* note 4.
271. CAL. HEALTH & SAFETY CODE § 130290.
272. *Id.*
273. *Id.*
274. *Id.*
275. Stephanie Russo Carroll et al., *Indigenous Data Governance: Strategies from United States Native Nations*, 18 DATA SCI. J. 31 (2019).
276. *Id.*
277. Aila Hoss, *Securing Tribal Consultation to Support Indian Health*, 14 NE. U. L. REV. 155, 170–75 (2022).
278. Centennial Accord, GOVERNOR'S OFF. INDIAN AFFS., <https://goia.wa.gov/relations/centennial-accord>.
279. OR. REV. STAT. § 182.164(3).
280. N.M. STAT. ANN. § 11-18-3.
281. 25 U.S.C. § 1621m(b) (2012).
282. *Currently Funded TECs*, INDIAN HEALTH SERV., <https://www.ihs.gov/epi/tecs/currently-funded-tec/> (last visited Sept. 28, 2022).
283. 25 U.S.C. § 1621m(b) (2012).
284. *Tribal Epidemiology Centers: HHS Actions Needed to Enhance Data Access*, *supra* note 81; Udall, Murray, Pallone, Grijalva, Gallego Raise Concerns about Tribes Being Denied Access to Critical Federal COVID-19 Data, *supra* note 4; Darius Tahir & Adam Cancryn, *American Indian tribes thwarted in efforts to get coronavirus data*, POLITICO (June 11, 2020), <https://www.politico.com/news/2020/06/11/native-american-coronavirus-data-314527>.
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287. *Urban Indian Organizations*, INDIAN HEALTH SERV., <https://www.ihs.gov/urban/urban-indian-organizations/>.
288. See 45 C.F.R. § 164.512(i); *Health Information Privacy – Research*, U.S. DEP'T OF HEALTH & HUM. SERVS. (June 13, 2018), <https://www.hhs.gov/hipaa/for-professionals/special-topics/research/index.html> (last visited Aug. 24, 2022).
289. See 45 C.F.R. § 46 for the Common Rule provisions. See also *Office for Human Subjects Research Protections*, U.S. Dep't of Health and Hum. Servs., <https://www.hhs.gov/ohrp/index.html> (last visited Aug. 24, 2022).
290. GREAT SCHS. P'SHIP, *The Glossary of Education Reform Aggregate Data* (July 23, 2015), <https://www.edglossary.org/aggregate-data/>.
291. PAN AM. HEALTH ORG., *Why Data Disaggregation is Key During a Pandemic* (2020), <https://iris.paho.org/bitstream/handle/10665.2/52002/Data-Disaggregation-Factsheet-eng.pdf?sequence=19#:~:text=Disaggregated%20data%20refers%20to%20the,elucidate%20underlying%20trends%20and%20patterns>
292. TEACHING FOR DIVERSITY AND SOCIAL JUSTICE: A SOURCEBOOK, *supra* note 7.
293. NAT'L COMM'N TO TRANSFORM PUB. HEALTH DATA SYS., *White Paper: Transforming Public Health Data Systems Supplemental Materials*, 2 (May 2021).
294. Carroll et al., *supra* note 274.
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299. Sweeney et al., *supra* note 219.
300. U.S. DEP'T OF HEALTH AND HUM. SERVS., OFF. OF DISEASE PREVENTION AND HEALTH PROMOTION, *Healthy People 2030*, <https://health.gov/healthypeople/objectives-and-data/social-determinants-health>.



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