Croal Services Group

Identifying Governmental Public Health Systems Barriers and Facilitators to Complying with and Expanding Race and Ethnicity Data Disaggregation Standards

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Introduction

This report is an internal resource developed to inform the Robert Wood Johnson Foundation's programmatic strategy on data disaggregation. Our team was charged with understanding the *logistical barriers* to racial and ethnic data disaggregation within governmental public health systems.

The Foundation also funded related projects focused on the statistical and legal barriers. Our team both identified barriers that cut across Tribal and governmental public health systems nationally, and examined issues within five states that the Foundation identified as places for potential demonstration sites: California, Michigan, Nevada, New York, and Washington. The context of this work, our approach, and a summary of our research findings are provided in the following pages. We conclude with commentary about considerations for potential future strategic directions.

The Conundrum of Data Equity in a Racialized Caste System

As we examine the logistical barriers to racial and ethnic data, it is necessary to ground race in its proper context within our nation's history. In her book, *Caste: The Origins of Our Discontents*, Isabel Wilkerson provides this commentary on race as a social construct, "Race is fluid and superficial, subject to periodic redefinition to meet the needs of the dominant caste in what is now the United States." Indeed, we have witnessed the shift of race as a social construct in the categories that have been continuously redefined by the Census Bureau since 1890. The five current OMB categories for race are inaccurate and outdated at best, yet are undeniably political; tied to critical resources, opportunities, and assumptions that determine the hierarchical placement of individuals and communities within the nation's caste system.

Even as we advocate to broaden Office of Management and Budget (OMB) categories, defining race and ethnicity within standards founded in and upheld by white supremacism presents a conundrum. What are we attempting to measure? To what end? According to Kauh, Read and Scheitler (2021), "Data inequity should effectively be considered a form of systemic racism wherein data collection, analysis, and reporting policies, practices, and norms continue to disproportionately exclude certain communities from access to

opportunity and resources." These measures indirectly capture different dimensions of systemic racism. However, as we fight to deconstruct race, we are still wed to the need for using this social construct as a tool for advocacy. Further, we are on the precipice of a crossroads. Health departments across the nation are confronting the reality of needing to grapple with how to capture individuals' full identities beyond race, and an exponential increase in the multiracial population. Recent Census results revealed a [276% growth in the multiracial population](#) in the last decade. As the fastest growing racial group, this category alone may hold the potential to help the nation reconceptualize how we perceive and capture racial and ethnic identities.

The Centers for Disease Control and Prevention (CDC) has a [race code list](#) of over 900 categories that are currently aggregated into the five OMB race categories. As the multiracial population grows within such an extensive list, so does the need to check more than one box. Multiracial individuals are increasingly outlying the traditional concept of fitting neatly into one racial or ethnic category. This phenomenon has created the conditions and opportune time for health authorities to rethink race category totals that equal 100% and move beyond one-dimensional perceptions of identity that have been reduced to a single option.

Defining Data Disaggregation and Data Equity

Data disaggregation and data equity are related yet distinct concepts. *Data disaggregation* is the collection, provision, and reporting of data by demographic subcategories. *Data equity* is the collection, provision, and reporting of demographic data that takes into account the equity consequences, sociopolitical nature of the category definitions, and the provision of data to sovereign Tribal nations. While disaggregating within a racial or ethnic category may be an act in data equity for some populations (e.g., Asian Americans and Pacific Islanders), data equity may mean creating a new category for others (e.g., Middle Eastern/North African; MENA), or in the case of American Indian and Alaska Native (AI/AN) Tribes, compliance with laws and treaties that mandate Tribal data sovereignty. The distinction between these two concepts was critical to define as our team sought to understand the logistical barriers to race and ethnicity data equity, as opposed to those related solely to stratifying racial and ethnic data that adhered to the status quo.

Data equity is the collection, provision, and reporting of demographic data that takes into account the equity consequences, sociopolitical nature of the category definitions, and the provision of data to sovereign Tribal nations.

Focusing on Tribal and Governmental Public Health Systems During the COVID-19 Response

The scope of data equity extends well beyond health. And, the scope of health data encompasses more than governmental public health surveillance data. The Tribal and governmental systems that produce public health surveillance data, however, became the focus of our research in light of the COVID-19 pandemic response. In early 2020, as COVID-19 captured our nation's attention, we witnessed the vast majority of our governmental systems fail to produce adequate and timely epidemiological data by race and ethnicity that could be used to inform decision-makers and the public. These systems failures allowed our team to use the pandemic as a window into understanding pre-existing and widespread logistical barriers to race and ethnicity data equity more broadly.

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Methods

This research grew out of earlier work funded by the
Foundation to understand the landscape of community
opposition to data disaggregation within certain racial
and ethnic communities of color.

While we previously found that some community opposition to data disaggregation does
exist, more pervasive and underlying obstacles appeared to be tied to logistical barriers
within and across governmental public health systems. The qualitative methods we used
reflect an approach to surface and explore these logistical issues with narrative detail.

Tribal and U.S. governmental public health systems are diverse in structure. From a birds
eye view, the complexity of these systems as a whole is a challenge to navigate. Therefore,
we conducted background research to determine how to best describe these systems
in the context of data equity, Tribal data sovereignty, and logistical issues. This included
reviewing related journal articles, reports, news media, and consulting with expert
advisors. To deepen our understanding of the nuances within and across the systems, we
also conducted interviews with over fifty-six subject matter experts. Approximately fifteen
were focused on AI/AN populations and Tribes. Altogether, the subject matter experts we
engaged were Tribal, state, and local public health practitioners in California, Michigan,
Nevada, New York, and Washington, and experts from across the nation.

Our interviews were conducted during the COVID-19 pandemic, with governmental
public health under extraordinary scrutiny and demand. To encourage participation,
we promised confidentiality to our interviewees and shared that no identifiable
information would be revealed in our report. Despite this, we still experienced some
outright declines and multiple interviewees that needed to obtain approval before
participating. We also had four participants who requested to provide written answers
in lieu of an interview. In these cases, we honored their requests.

Findings

AI/AN Equity and Tribal Sovereignty

Understanding the history of how the U.S. was settled, the inequities this created, and the sovereign status of the 574 federally recognized Tribes in the U.S. is central to advancing data equity among American Indian and Alaska Native (AI/AN) communities, particularly Tribes. In addition to being considered a racial group, AI/AN populations have a distinct political status. This means that data equity among AI/AN populations is essentially two-part:

1. ensuring AI/AN people are meaningfully, ethically, and accurately represented in data, and

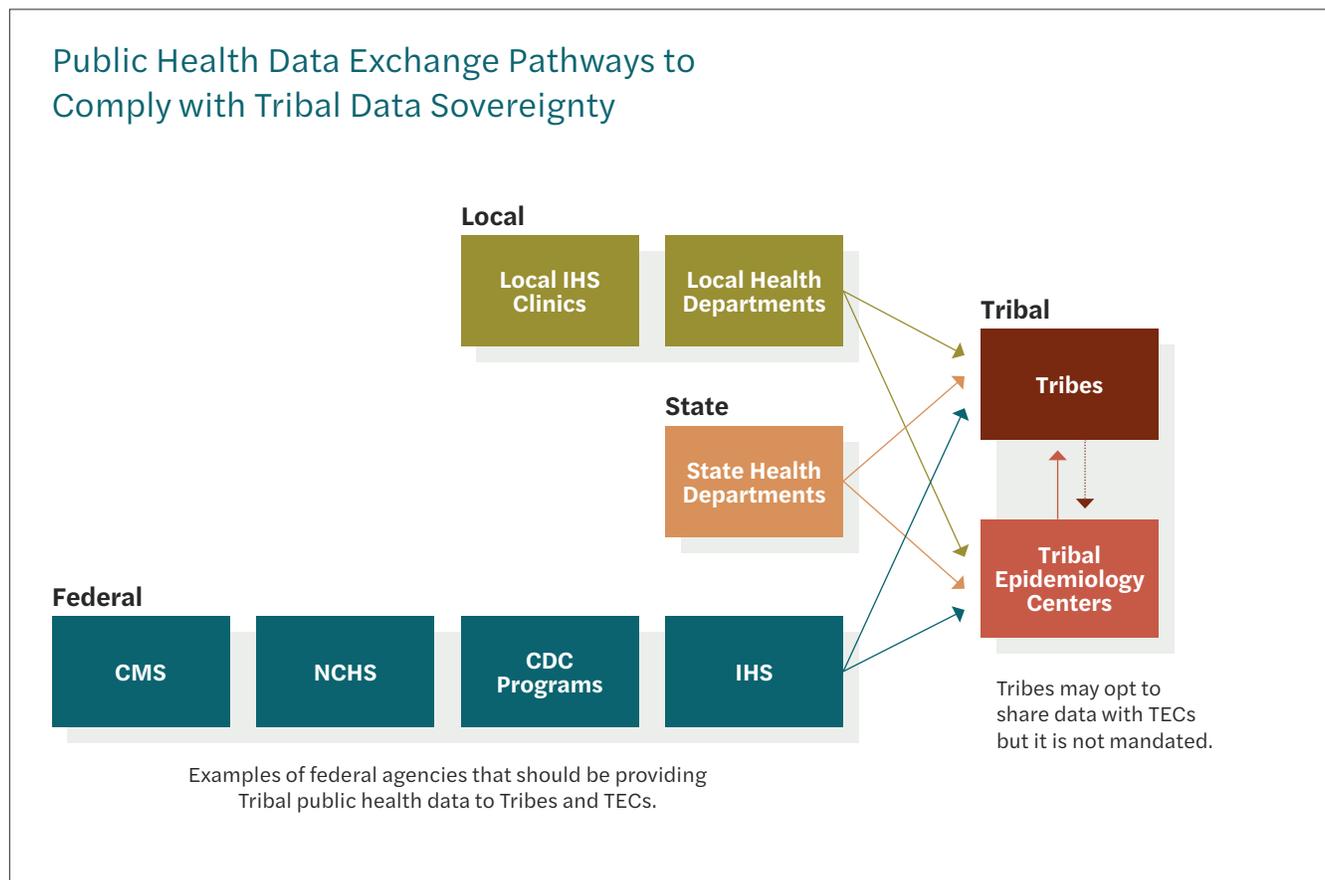**2.** recognizing and upholding Tribal data sovereignty.

Tribal data sovereignty is the right of a nation to govern the collection, ownership, and application of its own data. It derives from Tribes' inherent right to govern their peoples, lands, and resources. Unlike other racial and ethnic groups, the U.S. has a federal trust responsibility to provide education, housing, and healthcare services to enrolled members of federally recognized Tribes. Members of federally recognized Tribes also have legal rights to health care established by various treaties and case law including, but not limited to, the Snyder Act of 1921 (P.L. 83-568), the Indian Health Care Improvement Act, H.R. 1167, and the Patient Protection and Affordable Care Act (P.L. 111-148). Executive Order 13175 (2000) requires federal departments and agencies to consult with Tribal Nations on the development of any federal policies that impact Tribes, with the aim of strengthening government-to-government relationships between Tribal Nations and the federal government. Agreements are also a useful tool in facilitating collaboration between Tribal Nations and states. It is important to note that, given the U.S. is a federation, Tribal sovereignty necessitates government-to-government relations at both the state and national levels. These laws and treaties are the basis of Tribal data sovereignty and ownership.

TRIBAL PUBLIC HEALTH SYSTEMS

As sovereign nations, Tribes have jurisdictional public health authority. Theoretically, all 574 federally recognized Tribes could have their own unique public health systems. In reality, public health in Indian Country is severely under-resourced as a result of longstanding, deeply entrenched inequities. Tribal epidemiology centers (TECs) were formally recognized as designated public health authorities in 2010 when the Indian Healthcare Improvement Act was reauthorized. This Act grants TECs access to federal, state, and local data about their peoples, lands, and resources to manage public health issues and provide epidemiologic services to Tribes. Twelve TECs serve federally recognized Tribes in geographic areas that overlap with administrative designations established by Indian Health Services (IHS) (see Figure 1.). IHS has 161 offices and facilities in the twelve regions.

FIGURE 1

A Map of Twelve Tribal Epidemiology Centers that Serve Federally Recognized Tribes

Source: Tribal Epidemiology Centers

Within the CDC's Center for State, Tribal, Local, and Territorial Support (CSTLTS), the Office of Tribal Affairs and Strategic Alliances (OTASA) is the link between Tribes, CDC, and the Agency for Toxic Substance Disease Registry (ATSDR). Along with IHS, these key federal entities could play a more substantial role in ensuring AI/AN data equity and Tribal data sovereignty.

To fully honor and uphold Tribal data sovereignty related to public health surveillance, Tribes and TECs should have access to, ownership of, and receive their public health data in a timely manner from the relevant federal agencies (e.g., CDC programs, CMS, NCHS, IHS, etc.), state health departments, local health departments, and local IHS facilities.

FIGURE 2

Public Health Data Exchange Pathways to Comply with Tribal Data Sovereignty

Local
Local IHS Clinics
Local Health Departments

State
State Health Departments

Tribal
Tribes
Tribal Epidemiology Centers

Federal
CMS
NCHS
CDC Programs
IHS

Examples of federal agencies that should be providing Tribal public health data to Tribes and TECs.

Tribes may opt to share data with TECs but it is not mandated.

TRIBAL DATA SOVEREIGNTY BARRIERS

Previously Identified Barriers

In the previous phase of our research, we sought to understand the potential for opposition to data disaggregation among AI/AN communities. Interviewees named Tribal data sovereignty as a core data equity issue. Specific barriers to Tribal ownership of data were identified as:

- small sample size being cited as reasons for AI/AN population data not being provided and reported,

- AI/AN people often being racially misclassified, often as white,

- insufficient or non-existent data sharing agreement policies and practices that allow for Tribes and TECs to access their data in a routine and timely manner, and

- Tribal affiliation often not being collected, making it difficult to identify which data are specific to Tribes; further complicating the issue, some Tribes do not want Tribal affiliation data to be collected while others do.

In addition to Tribal affiliation, there are several related demographic concepts that require consultation with Tribes to determine which data points are appropriate to collect, track, and/or report. These demographic concepts include:

- Tribally enrolled (enrollment differs from affiliation in that it confers membership),

- Tribal descendant, but not enrolled,

- self-identified AI/AN, and

- member of a state recognized tribe, etc.

For the current phase of our research, we aimed to better understand the barriers to effective data sharing related to Tribal data sovereignty. In over fifteen conversations with state health department staff, TECs and Urban Indian organizations, three main themes emerged: (1) unacknowledged and widespread unawareness of Tribal and TEC public health authority, and how it relates to data sharing, access, and ownership; (2) limitations of data sharing agreements; and (3) inadequate data quality and data systems. Underpinning these issues are capacity challenges, especially the high turnover of core personnel across relevant stakeholder entities—i.e., TECs, Tribes, and local, state, and federal agencies. Overall, we found that the issue of data sharing requires a multi-pronged approach; that is, no single intervention alone will adequately address the systemic barriers.

Unacknowledged and widespread unawareness of Tribal and TEC public health authority, and how it relates to data sharing, access, and ownership

The HIPAA Privacy Rule recognizes the need for public health authorities to have access to protected health information to carry out their duties in identifying threats to the health and safety of the public. Accordingly, the Rule permits covered entities to disclose protected health information without authorization for specified public health purposes. Tribal governments' rights to access and own their public health data are often ignored, overlooked, or misunderstood. As a result, Tribes and TECs are faced with having to prove their public health authority, leading to costly and time consuming legal and administrative hurdles that other public health authorities do not typically encounter. We learned from our interviewees that some state health departments obviate their responsibilities to comply with Tribal data requests, citing it as a "federal government issue." Compounding this issue, memorandums of understanding (MOUs) or other legal mechanisms that facilitate Tribes accessing their data are rare, and if in place, are plagued with additional logistical obstacles. These challenges are not a matter of legal precedent but reflect the combined effects of structural bureaucratic barriers and an unawareness or unwillingness to recognize and implement the law.

Among the five focus states we examined, there are legislative efforts to increase understanding of Tribal sovereignty. While Tribal Consultation/Urban Confer are official processes that are nominally required of federal agencies by executive order, this requirement does not extend to state government agencies and is rarely explicitly delineated in state legislation. This can make Tribal-state relations difficult to navigate. An exception is Washington State's Centennial Accord, which aims to "respect the sovereign status of the parties, enhance and improve communications between them, and facilitate the resolution of issues." For more than 30 years, Washington has had a government-to-government agreement with Tribal Nations that states the Washington Department of Health will not engage in any work or activities that impacts Tribes without consulting with them in advance. To support the Accord, the state also partners with TECs in the region including the Northwest Portland Area Indian Health Board and the Urban Indian Health Institute.

In Michigan, Governor Whitmer passed Executive Directive 2019-17 in October 2019 which reaffirms and extends Michigan's commitment to recognize the sovereignty and right of self-governance of Michigan's federally recognized Tribes, and mandates state agencies adhere to these principles. The Directive also requires state agencies to provide annual training on Tribal-state relations for all employees who either interact directly with Tribes or whose work has direct implications for Tribes. Interviewees shared that the Inter-Tribal Council of Michigan, Inc. (ITCMI) has been helpful in facilitating communication between the state and Tribes. While each individual Tribe is tasked with developing their own data sharing agreement, ITCMI supports drafting or reviewing these agreements, with the Tribe having ultimate decision-making power.

Despite these state legislative efforts, many Tribes and TECs still do not receive their data or find that the data they do receive is incomplete and/or untimely. As such, laws and regulations are important policy levers, but the existence of these interventions alone is not enough to invoke widespread change. Legislatures must allocate adequate funding to create an infrastructure with the requisite capacity that supports equitable Tribal relations. All too often, the work of building Tribal-state relationships and data sharing is the responsibility of a single state health department employee who has many other responsibilities and supports multiple Tribal Nations with varying needs. As a glimmer of hope, we learned from interviewees that Tribal-state relations have been strengthening out of a need to collectively respond to COVID-19. The current climate suggests an opportunity to leverage this increased cooperation to improve Tribal data sovereignty and data exchange beyond the pandemic.

Limitations of Data Sharing Agreements

Data sharing agreements are formal contracts that outline how to obtain and/or share data between entities. According to NativeDATA, a free online resource that offers practical guidance for Tribes and Tribal-serving organizations, data sharing agreements often outline:

- When data will be provided and how long the recipient will use it for;

- How data will be provided to the recipient;

- How the recipient intends to use the data;

- Any restrictions on how data can be used or shared;

- Who owns reports that contain data findings;

- The review process for publishing or sharing reports;

- Processes for protecting Tribal and individual confidentiality;

- Ways the receiver will make sure data are secure;

- Actions that must be taken if data are stolen or lost;

- Who is responsible for overseeing the process if data are stolen or lost;

- The financial costs of data sharing and who will pay; and

- What will happen to data after the period of agreement is over.

The development of data sharing agreements is both time and relationship intensive. Staff capacity challenges hinder the adoption and maintenance of data sharing agreements. Knowing and engaging points of contacts, including Tribal leadership in each Tribal community, having open lines of communication, and building trust are vital for timely and effective data sharing. Increasing health department staff capacity through additional dedicated Tribal-specific staff, including Tribal liaisons and Tribal epidemiologists, are invaluable investments. Many of these staff have been pulled away from Tribal work and are currently focused on COVID-related projects. Having dedicated state Tribal staff to liaise between the state, Tribes and TECs can ensure state data is accessible, help

facilitate existing and new data sharing agreements, and assist with data analysis and timely reporting. Equally important is ensuring Tribes and TECs have the capacity to enter into and maintain data sharing agreements with health departments.

While data sharing requires buy-in from several parties across multiple organizations, no one-size fits all approach is ideal. This is because Tribes and government agencies vary in terms of size, capacity, and geography, for example, larger Tribes can span across states whereas smaller Tribes can be within a single county. These jurisdictional realities create an additional barrier to understanding Tribal Nations and an additional layer of logistical complexity to data sharing agreements.

Beyond the logistical challenges of developing data sharing agreements, once in place, these agreements are often time-limited and may be in effect for as little as one year. Exacerbating this issue is widespread staffing turnover at Tribal organizations, federal agencies, and state and local health departments. The departure of leaders that may have been involved in establishing data sharing agreements results in institutional knowledge gaps. Consequently, health departments, Tribes and TECs must often restart the time-intensive process of re-education or reestablishing agreements as new points of contact are onboarded. Multiple interviewees noted the need for longer-term data sharing agreements of at least 3-5 years that could potentially help mitigate these obstacles. In addition, the development and dissemination of Tribal data sharing tools (e.g., data agreement templates) can accelerate the agreement process and serve as a reference for precedent if utilized.

Ignorance of Tribal sovereignty also extends to conflicting views on who owns and can give permission to share data, particularly data coming from IHS. Bidirectional data sharing is an ongoing challenge. Tribes often share data with the state, CDC, or IHS and do not receive data back at the regularity or transparency they desire. There are also instances where Tribes own data that the state and IHS cannot access. Victoria Warren-Mears, Director of Northwest Tribal Epidemiology Center, notes in her comments on the NativeDATA project that bidirectional relationships are important because "there might be a story that goes along with the data and that story isn't yours to tell because you are not immersed in the community." She further underscores that the interpretation of data:

> Belongs to the Tribal members who are able to contextualize the data so that elements of history, culture, and community strengths are accounted for. It is this bidirectional process of data caretaking on the part of NWTEC and data interpretation on the part of Tribes that moves intervention science forward, promotes community buy-in, and ultimately improves health outcomes.

Long-lasting policy or legislation that is not as vulnerable to staff or administrative turnover, or time-limited data sharing agreements, can help ensure that data flows between parties.

Inadequate Data Quality and Data Systems

A core issue identified in multiple interviews is the quality of the data that is being received by TECs, Tribes, and health departments. Data is only as good as what is initially collected by providers. Missing race and ethnicity data, and racial misclassification are recurring issues at the point of collection that impact the sharing of quality data. Many systems are not coded for multiracial populations which disproportionately impacts AI/AN populations that also identify as Hispanic. Promising solutions to address these issues include:

- having standardized and mandatory fields to collect race and ethnicity data;

- oversampling, automatic matching to health insurance exchanges, developing a master patient index, etc.; and

- linking data to Tribal records, and birth and death records.

Closely tied to data quality challenges are system interoperability issues, wherein data travels in silos to the federal level. These data silos are created by separate data collection systems that do not "speak" to one another and/or have different requirements and data permissions. Relevant federal agencies, such as CDC, IHS and VA, do not collaborate in monitoring or sharing data across systems which makes data quality, accuracy, and consistency a challenge. For IHS, in particular, the use of different data collection systems has been an ongoing challenge. Some Tribes use RPMS (the IHS data collection system) to report their data, but Tribes may also choose their own electronic health systems as authorized through the Indian Self-Determination and Education Assistance Act (P.L. 93-638). Consequently, capturing reports from all of the different Tribally-operated systems is burdensome. Across jurisdictions, agencies are hindered by siloed funding and outdated data collection systems which have delayed daunting data modernization efforts.

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FACILITATING TRIBAL DATA SOVEREIGNTY

More education is needed on existing laws and treaties related to data sharing, and how they translate into practice and relate to surveillance data for data owners, users, and policymakers. There is also a great need for Tribal law expertise in every state health department, as well as Tribal advocates or liaisons who can raise awareness of the unique obstacles Tribes face because of failures to recognize their sovereignty.

As an example, Tribes located in New Mexico have ownership of their data because recognition of Tribal sovereignty is embedded in state and local health department operations. New Mexico has a robust Tribal liaison structure with positions in each state agency that report directly to the Governor. The state has a Tribal epidemiologist specifically focused on Tribal data and interfacing with Tribal Nations. Tribes have access to a portal where they can directly access their data. Tribes own any data for people that live on Tribal land 75% or more of the time, and the state can only do projects with that data if given Tribal permission.

Despite the vast challenges, we learned about examples of systems, processes, and procedures that advance Tribal sovereignty and effective data sharing. Promising solutions include:

- fully funded Tribal liaison positions at the state level,
- mandating data sharing in federal and philanthropic funding agreements,
- updating ECR/ELR standards for collecting and transmitting race and ethnicity data,
- providing financial incentives for completing race and ethnicity data,
- requiring race and ethnicity data fields be completed,
- providing additional funding and/or amending existing CDC funding to support, TECs' work, including providing funding for oversampling of AI/AN populations,
- conducting audits to quantify and address the amount of missing data, and address data gaps, and
- establishing government-to-government agreements at the state level.

To uphold and honor Tribal sovereignty, significant and urgent action is needed to advance effective data sharing between Tribes and federal, state, and local health systems. This includes overall education on data sovereignty and data ownership, as well as continued efforts to recognize the public health authority status of Tribes and TECs, not just in policy but in practice.

U.S. Governmental Public Health Surveillance Systems and How Race and Ethnicity Data Gets Compromised Across Data Exchange Pathways

The U.S. public health system as a whole represents a complex interplay of multiple systems with jurisdictional authority to varying degrees and levels. At the state level, CDC recognizes seven types of governance structures; however, these types can be distilled into three major categories: centralized, decentralized, and hybrid. In a centralized system, both statewide and local public health activities are carried out by state health department employees. A decentralized system has a separate state health department and local health departments that operate with jurisdictional autonomy. A hybrid model is a mix of the state and locals carrying out public health activities at the local level. These varying structures have implications when considering data equity policy and practices that cut across systems.

While not all public health surveillance activities are mandated, tracking state reportable and national notifiable diseases is regulated and represents the epidemiologic surveillance activities that are vital to controlling outbreaks of utmost concern, such as COVID-19. The Council for State and Territorial Epidemiologists (CSTE) is responsible for annually determining which diseases are notifiable. Figure 3 provides an overview of the logistics that are required once a notifiable case has been identified, and shows how data are supposed to flow through the National Notifiable Disease Surveillance System (NNDSS).

FIGURE 3

Source: Centers for Disease Control & Prevention
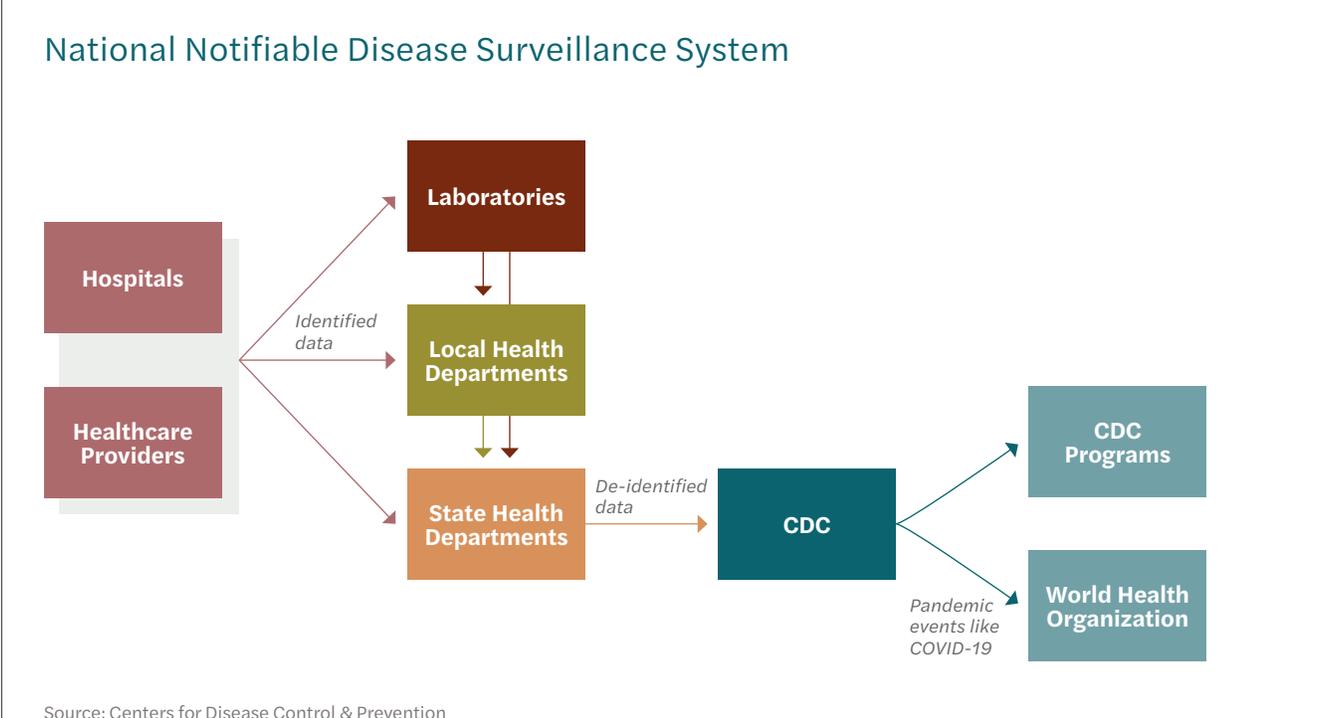
The NNDSS graphic can also be augmented to illustrate points along the data exchange pathway where race and ethnicity data may be compromised in validity and reliability (see Figure 4.). Local and state health departments are supposed to receive data about state reportable conditions from regulated providers (i.e., hospitals, healthcare providers, and laboratories). Regulated providers, however, may have poor quality or missing race and ethnicity data due to:

■ A provider not being trained and/or feeling comfortable asking about a patient's race and ethnicity and leaving the data field blank or misclassified. During outbreak surges like COVID-19, they may also feel overburdened and skip or guess at this data.

■ A patient may not feel represented by the race and ethnicity category options available or may not understand what they mean, leaving the data field blank or misclassified.

■ Hospitals, providers, or labs may have proprietary electronic medical or health records that have been set to race and ethnicity categories that are different from each other's and/or the health department's, creating the need to merge data fields that are not harmonized, which then leads to missing and misclassified data. Furthermore, some regulated providers may only have paper records where reportable cases are faxed to the health department and then need to be manually entered into a database, raising the probability of keying errors.

■ Regulated providers have a high burden of reporting to multiple entities (e.g., see CMS diagram on hospital reporting) that is either mandated by law and/or required for the reimbursement needed to operate business. Race and ethnicity value sets in these reporting requirements are often incongruent, and the majority of data are housed within proprietary electronic records that can be costly to change.
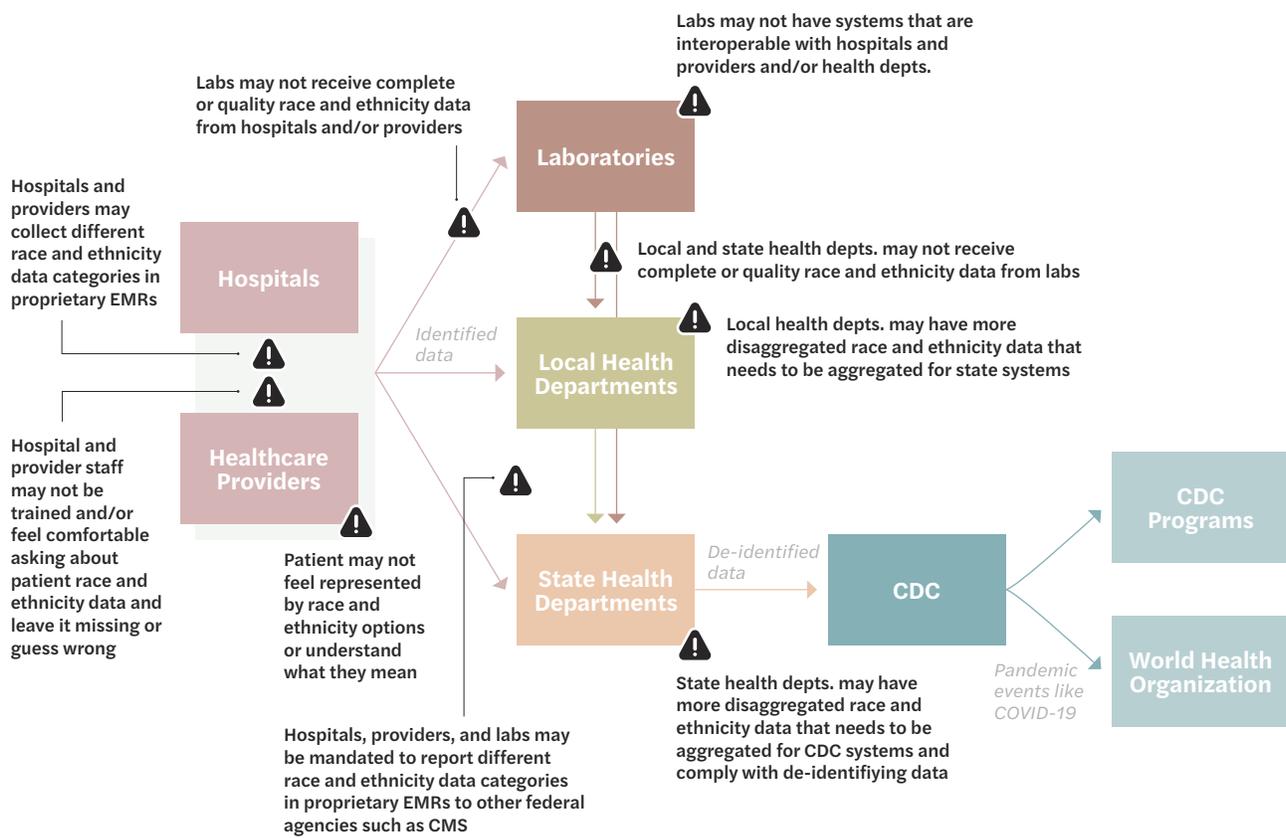
We often heard from interviewees working in public health departments that the data they have is only as good as the data they receive from the multitude of regulated provider inputs. An increase in pop-up laboratories and COVID-19 testing sites has burdened health departments with onboarding data exchange procedures and requirements. This was a commonly reported reason for missing race and ethnicity data across states. Health departments must also contend with the challenge of providing and reporting out case data that is timely versus fully complete. As such, a case report that is missing demographic information such as race and ethnicity will likely get counted, even with incomplete demographics, especially during crisis events with extremely high case counts that surge like COVID-19. Even if health departments prioritize the completion of missing data, conducting case investigations is costly, time consuming, and untenable for agencies that may be under-resourced.

In situations when a local, state, or Tribal health department is able to collect more granular disaggregated race and ethnicity data, aggregating the data is necessary to comply with NNDSS data format requirements further up the reporting pathway (i.e., state or federal data systems). Furthermore, in compliance with IHCIA and HIPAA, Tribal agencies and TECs should have access to their data. They should also be receiving their data back from local and state health departments, local IHS clinics, and federal agencies. In practice, however, this data exchange is inconsistent and rare.

The barriers to race and ethnicity data in the NNDSS represent just one of the many surveillance data exchange systems in governmental public health. Examples of other surveillance activities that have similar multi-jurisdictional data exchange pathways are cancer registries, the Immunization Information Systems (IIS), and the Behavioral Risk Factor Surveillance System (BRFSS), among many others. While distinctions between these systems exist, the NNDSS is useful in illustrating the kinds of universal logistical obstacles to race and ethnicity surveillance data that can occur when multiple entities are required to exchange data.

FIGURE 4

Race and Ethnicity Data Flow Obstacles in the National Notifiable Disease Surveillance System

Labs may not have systems that are interoperable with hospitals and providers and/or health depts.

Labs may not receive complete or quality race and ethnicity data from hospitals and/or providers

Hospitals and providers may collect different race and ethnicity data categories in proprietary EMRs

Laboratories

Local and state health depts. may not receive complete or quality race and ethnicity data from labs

Hospitals

Local health depts. may have more disaggregated race and ethnicity data that needs to be aggregated for state systems

Identified data

Local Health Departments

Hospital and provider staff may not be trained and/or feel comfortable asking about patient race and ethnicity data and leave it missing or guess wrong

Healthcare Providers

Patient may not feel represented by race and ethnicity options or understand what they mean

State Health Departments

De-identified data

CDC

CDC Programs

World Health Organization

Pandemic events like COVID-19

State health depts. may have more disaggregated race and ethnicity data that needs to be aggregated for CDC systems and comply with de-identifiying data

Hospitals, providers, and labs may be mandated to report different race and ethnicity data categories in proprietary EMRs to other federal agencies such as CMS

Levers for Data Equity Across the U.S. Public Health System

As we learned about the kinds of logistical barriers that impede data equity within surveillance systems, levers that facilitate data equity also emerged: leadership, community engagement, data standardization considerations, and data modernization. While beyond the scope of our report, legal approaches and innovative statistical methods can also play key roles in a comprehensive data equity strategy.

LEADERSHIP

Leadership can be a pivotal lever and is foundational for setting a vision for data equity. Political will in the form of a commitment to a strategic vision around data equity shapes priorities, action, and expectations. Leaders can mandate the collection of race and ethnicity data, convene stakeholders to create and adopt standards, and enact the use of data to inform policy and decision-making.

A silver lining in the pandemic has been the creation of more formalized leadership roles focused specifically on equity. While some of these positions have executive level decision-making authority, other positions like equity officers have been created so that equity issues remain front and center and are fully embedded into workstreams. The standing up of equity offices and centers, task forces, health equity and data equity committees are examples of the various ways in which state and local leaders are deliberately creating awareness around health equity, and demonstrating commitments to internal and external reform. These channels are laying the groundwork for a transition into permanent cross-sector infrastructure that can promote and implement equitable policies and practices.

Federal leadership is desired to resolve issues around data sources, data sharing, and national standards where states and local health departments are subject to federal laws and regulations. Additionally, federal agencies such as the Office of the National Coordinator for Health Information Technology (ONC) can incentivize, set restrictions and issue fines for non-compliance in circumstances where they have oversight of accreditation requirements, such as with EMRs. In this instance, relevant federal agencies can mandate specific data elements, including race and ethnicity, and electronic data system workflows can be tied to reimbursement. Department of Health and Human Services (HHS) mandates, first introduced in 1997 as the Data Inclusion policy and modified in 2011 through Affordable Care Act (ACA) Section 4302, resulting in data collection standards for race and ethnicity, language, sex, and disability status, are further examples of how the federal government can use its authority to increase data quality across levels of surveillance systems.

Leadership is not just limited to federal and state levels. In many cases, local health departments (LHD) are frontrunners in data equity work. In decentralized and hybrid states, autonomous LHDs have the authority to set and implement strategy. At local levels, health departments are experimenting with innovative workarounds, including:

- Race and ethnicity write-in options for surveys

- Reporting the multiracial category in various ways, and with totals that do not always equal 100%

- Capturing community affiliation as opposed to racial and ethnic identities

- Using an integrated master data hub to link missing race and ethnicity data available in other data sets

- Helping providers adopt EMRs that are connected to RHIOs (Regional Health Information Organizations)

- Partnering with cloud-based vendors that can leverage EMRs to complete missing race and ethnicity data

COMMUNITY ENGAGEMENT

Health departments that are making strides towards data equity have meaningfully engaged racial and ethnic communities in their processes and decisions. Co-creating with communities is a necessary step to build rapport and address histories of harm and data misuse. Redefining the definition of expert to include ownership of one's unique, lived experience centers community voices and radically changes the traditional portrait of who is seated at the table. Furthermore, expanding the definition of expert to include groups that are impacted by policy and decision-making ensures communities are engaged around their own data, and can provide context and insight throughout the data lifecycle. This shift supports the creation of more meaningful racial and ethnic categories that are reflective of shared identities, and allows communities to recognize themselves in value sets, paving the way for more complete and valid data. The sharing back of data is a natural step in this framework, where communities are the primary audience.

True community engagement is dynamic. Health departments that are cultivating strong community relationships have expressed the notion that it is an iterative process through which conversations and approaches, and even definitions of community have evolved. Tensions are often present as meeting the needs of multiple constituencies often conflicts with capacity, systems, and resource limitations. However, transparency in consultation can ultimately strengthen relationships between communities and state and local health departments. Formally and regularly soliciting community input is a best practice that can bridge the gap between data and response strategies, and help health departments further understand how race and ethnicity data should be disaggregated.

DATA STANDARDIZATION CONSIDERATIONS

Enlisting meaningful race and ethnicity categories that resonate with the communities they intend to describe is a crucial step to enhancing data equity. In our interviews, we heard contrasting ideas about what actions are needed to address race and ethnicity data standards. On one hand, the uncoordinated and inconsistent race and ethnicity value sets used by federal agencies were identified as an impediment. This practice leads to confusion in the field and inefficient workflows for local, Tribal, and state health departments, and regulated providers that need to report data to multiple federal agencies. We heard calls for federal agencies to align and create a consistent standard for race and ethnicity data value sets. Consistency would allow for states, Tribes, TECs, and local health departments to potentially link cases across program surveillance systems and fill in gaps where race and ethnicity data were previously unknown. In contrast, we also heard support for abandoning any blanket requirement for health departments to collect and report race and ethnicity data that must adhere to national standards. This argument posits that national standards can impede the actual data value sets needed to best capture the unique racial and ethnic composition of a particular geographic jurisdiction. Here, the notion of standardization at a level as vast as the nation is counter to the intention of data equity. Our team suggests a constructive dialogue is needed that engages Tribal and public health stakeholders across levels of government to determine the kinds of data practices that are necessary to uplift data equity.

TRAINING

REaL (race, ethnicity, and language) data training can be integral to a strategy for strengthening surveillance data quality. REaL training is critical to mitigate feelings of hesitancy and reluctance for frontline staff who engage with patients, families and caregivers. This kind of training is also necessary outside of clinical settings for staff who are responsible for inputting, managing, and reporting data (e.g., laboratories and health department personnel). Comprehensive training should go beyond best practices for the collection of REaL data to help staff understand why race and ethnicity data is important, and how it will be used to inform resource allocation, policy, and program decisions. Linking training to broader efforts to advance equity can help people see how their actions are directly connected to improving health. We learned that information about training and best practices exists. The more pressing challenge is widespread implementation as effective training initiatives are expensive, time-consuming, and require institutional buy-in. Adoption is happening piecemeal and there is no well known organization solely focused on high quality data equity training in the sector.

DATA MODERNIZATION

Data modernization efforts encompass the types of technical logistics solutions that create efficiencies in public health data systems, which include transitioning from manual to electronic procedures, and establishing interoperability within and across surveillance data systems. Increased interoperability, for example, is needed between provider EMR systems and the data systems public health departments use to ingest provider data. Furthermore, increasing interoperability within a health department's data systems could open up the possibility of case matching across its surveillance systems. This could lead to more comprehensive epidemiological portraits of communities and the ability to fill in gaps where demographic data, such as race and ethnicity, are missing from datasets. The current infrastructure for data modernization, however, does not exist in many places due to funding and capacity limitations. Where some data modernization capacity does exist—e.g., use of electronic case or lab reporting (ECR/ELR)—it is not robust enough to be reliable in many states or localities, let alone at the national level. CSTE and ONC are two national stakeholders leading data modernization efforts.

Together these levers represent various high level pathways towards data equity. We also heard specific actionable recommendations from practitioners.

PRACTITIONER RECOMMENDATIONS

While there is promising progress unfolding in every focus state, opportunities exist to strengthen these efforts by leveraging facilitators of data equity. Our team heard the following cross-cutting recommendations from our interviewees as potential strategic investments that could be of benefit in all five states:

Leadership

- Create and define leadership roles at all levels to move equity work forward
- Develop state level plans for achieving data equity and sustaining race and ethnicity work
- Advocate for a national framework, federal agency alignment, and new standards for collecting and reporting race and ethnicity data

Community Engagement

- Convene conversations focused on data disaggregation that are led by and center racial and ethnic communities, especially communities of color

Training and Education

- Educate health departments on Tribal sovereignty and Tribal data requirements (data access, data sharing, data governance)
- Train health departments, laboratories, and providers on the importance of capturing race and ethnicity data, and how to ask race and ethnicity questions
- Provide guidance on how to capture full identities for multiracial individuals

Data Standards

- Align standards across public health surveillance systems to harmonize race and ethnicity data collection, provision, and reporting, and reduce provider and laboratory reporting burden

Data Modernization

- Provide and upgrade technology to increase Tribal Nations' and health departments' capacity to collect, manage, and retrieve data
- Code systems for a multiracial category option and the selection of more than one race and ethnicity category
- Upgrade systems to allow for management, analysis, and exchange of more granular race and ethnicity data

Compliance

- Require race and ethnicity data fields and pair requirements with incentives and penalties for provider and lab accountability

In addition to these cross-cutting recommendations, interviewees identified a mix of projects and ideas that have been included in the following state profiles.

State Profiles

Prior to this project, the Robert Wood Johnson Foundation funded a collaborative of five national civil rights organizations to conduct a landscape analysis that would inform data disaggregation policy recommendations. The analysis spanned all states and identified areas of opportunity to better the collection, analysis, and reporting of more granular race and ethnicity data. As a result of the landscape analysis, five focus states were chosen as potential demonstration sites for investments in strategies to advance data disaggregation. The states selected were California, Michigan, Nevada, New York, and Washington. These states vary in size and demographics, and in their readiness to adopt a vision and make progress on data disaggregation for data equity.

COVID-19 has transformed public health into a political battleground. Since the pandemic began, public health departments and leaders have been targeted as scapegoats, with some receiving death threats. Further, many public health departments have received public backlash for response strategies and publicized data. This harsh reality, coupled with the sheer burnout of employees, has caused a mass exodus in the public health workforce. These factors may have contributed to some interviewees' hesitancy to participate in this project, and in outright declinations. Therefore, the following profiles are based on information provided by a varied pool of state and local health department professional roles that were not uniformly represented across states.

We captured a select few perspectives of professionals in local health departments (LHDs), as it was out of the scope and unfeasible to speak to all LHDs across all five states. In some states, it is clear that LHDs are doing more data equity work than is being done at the state level. LHDs are not bound by the same constraints and large-scale coordination of jurisdictions as state health departments. Thus, conclusions about a state's readiness for data disaggregation must take its public health structure (i.e., centralized, decentralized, or hybrid) into account, as it is entirely possible for a state to have wide and varied gaps in readiness in places where locals have jurisdictional authority to set and lead their own strategies. In this project, the five select states we examined were all decentralized with the exception of Nevada which has a hybrid structure.

While most interviewees spoke very candidly, we observed this was the case primarily in places that have a clear strategy around data equity that has been articulated and embraced by leadership. In instances where interviewees were vague in responses, it could be inferred that not much is happening within the state or LHD to share with regards to data equity. Subsequently, we were able to compile more information on states that are actively confronting and working on data equity issues. Additionally, in cases where we received similar feedback across states, this information is captured in previous sections of this report. The following state profiles are provided to summarize the nuances of each potential demonstration state.

CALIFORNIA

California is currently home to 39.5 million residents and is projected to reach 45 million by 2050. Its $3.1 trillion economy is the largest in the nation and the fifth largest globally. According to the Public Policy Institute of California, more than a third of the state's residents are living in or near poverty as the wealth gap continues to widen. A quarter of the country's immigrants live in California. While California's Hispanic population makes it a minority-majority state, immigration from Asia has nearly doubled rates from Latin America since 2010. Multiracial residents are now the fastest growing population. In the last decade, the multiracial population has increased by 22% (faster than Asians at 10% and Hispanic at 14%). State's demographers predict another 21% jump in growth by 2030.

California's size and diversity by race, ethnicity, income, immigration status, Tribes, and a host of other factors, speaks to the complexity of the state's landscape and the multitude of barriers to data equity. Growing diversity and a booming multiracial population, coupled with a decentralized health model, creates a unique challenge for the state in its approach to data disaggregation. The state partners with 61 local health jurisdictions (LHJs), which operate autonomously to set their own budgets, implement strategies, and issue public health orders. Although a Local Coordination Team from the state interfaces with LHJs, the nature of decentralization not only inhibits the enforcement of standards across the state, but requires more time and resources on all fronts; for example, coordination between the state and LHJs, reconciling data between departments, quality assessment, consistency in messaging, and education for the state's many providers. While coordination presents many challenges, local expertise and focus underscore the benefits of a decentralized system.

Equity Framework

Prior to COVID-19, there were no dedicated equity roles on California's incident command structure that could help inform wider response strategies. The state had an Office of Health Equity with a leadership role that was vacant when the pandemic hit. COVID-19 quickly revealed the need for a formalized role with executive authority that would take equity into account in the state's emergency response, and oversee a formalized equity workstream in the state's organizational chart. Once the Office of Health Equity Deputy Director was appointed by the Governor, this role was embedded into the state's Incident Command System. The Equity Officer role is a position identified by BARHII as a priority investment in government and emergency response structures for an equitable recovery. This equity framework is defining programming at the state level and for LHJs which are adopting formal equity officer positions. In alignment with this strategy, California's governor created a health equity metric as part of the state's blueprint to reopen and has described equity as its North Star throughout all aspects of the response.

The California Equitable Recovery Initiative (CERI) further seeks to expand resources to address equity with a multi-pronged approach that will: 1) build infrastructure and organizational capacity; 2) leverage strategies and practices aligned with the COVID-19 Health Equity Playbook for Communities; 3) support prevention and mitigation of health disparities in COVID-19 and other health outcomes, and; 4) address structural and/or social determinants of health. The next phase of the state's response to the pandemic is outlined in the recently unveiled SMARTER Plan. This strategic approach builds on California's commitment to equity with strategies that will continue to address the needs of disproportionately impacted communities while increasing the state's preparedness to respond to COVID-19 and future emergencies.

Policy

In 2016, California's state legislature passed AB-1726 into law, mandating race and ethnicity data disaggregation for Asian, Native Hawaiian and other Pacific Islander groups. The state is currently implementing AB-1726 and coding systems to allow for the more granular data. A new bill that would expand the mandate for additional race and ethnicity groups was introduced in 2021, AB-1358, and is currently being considered in committee. AB-1358 would require further disaggregated data for Hispanic, Latino, Spanish, Caribbean, Black or African American, Native American, and Middle Eastern or North African groups.

These bills have not come without challenges, as California's privacy laws override the new legislation. In particular, some Pacific Islander advocates have expressed concerns over the state's data de-identification laws. Additionally, positioning the system for compliance will be a challenge as providers, labs, and the California Department of Public Health will need to overhaul systems to collect, manage, and provide disaggregated race and ethnicity data.

Community Engagement

Across the state, there is a desire to convene more discussions around data disaggregation with community-based organizations and leaders. Work with community groups started pre-COVID and continues to be an iterative, evolving process. At the state level, community engagement tends to be reactive as opposed to proactive, primarily because of time, staff capacity, and funding. Cultivating meaningful community relationships must be a formalized, ongoing process, and reach beyond just the advocacy groups currently pushing for further disaggregation. The state is making some effort towards this by contracting with approximately 250 community-based organizations over the course of the pandemic and through the creation of the Community Vaccine Advisory Committee. Tasked with the coordination of so many local health jurisdictions, the state may not always be the appropriate channel to convene stakeholders in a meaningful way. LHJs are more connected to local communities and their needs. However, there is acknowledgement at both the state and local levels that true community engagement is valued and necessary. Community partners must be engaged for missing context and insight, and the challenge is to balance this step with the need and expectation to release data quickly and accurately.

Data Surveillance Systems

California faced systems challenges similar to other states early on in the pandemic. The state's largest electronic disease reporting and surveillance system, CalREDIE (California Reportable Disease Information Exchange), was not equipped to handle the volume, scale or frequency of data input and output; however, building a new surveillance system and completing training was an impossible task in the midst of COVID-19 demands and budget constraints. CalREDIE is a legacy system that is used by the state and all 61 LHJs to some extent, with 58 LHJs using the system for notifiable communicable disease surveillance. Over 350 laboratories use CalREDIE to submit lab results using electronic laboratory reporting (ELR), however this number is miniscule compared to the thousands of laboratories active across the state.

Although CalREDIE has the ability to collect race and ethnicity data, early on in the pandemic staff were overwhelmed by the sheer amount of data input from high case numbers and were not entering this level of detail. This changed when the state prioritized and established a requirement to enter race and ethnicity data. Additionally, race and ethnicity data was often missing from case reports. Capacity, outdated and siloed systems across counties, and interoperability issues were compounded across the state as staff created workarounds to estimate true rates of race and ethnicity.

Surveillance system issues have been exacerbated by inconsistent reporting and completion of race and ethnicity data from the state's many providers and labs. Medical and provider communities responsible for collecting this data are critical partners on the front lines. Data is only as good as it is being reported, and the completion of data does not ensure accurate data. The state has little control over the collection and reporting of race and ethnicity data from external sources other than to provide guidance, as costs to upgrade EMR systems are within the purview of providers and health systems. As a result, health departments have invested critical time and resources into the review of lab data and quality improvement efforts to ensure standardized reporting practices. These have been costly investments across the state as thousands of new laboratories have popped up during the pandemic with no incentives or regulation to enforce data compliance.

California's systems were limited in the collection of more granular data beyond OMB standards. Further complicating this issue during the pandemic was that registries and EMRs did not accept multiple race codes or a multiracial category. Systems' inability to capture multiracial identities in their entirety has caused the inflation of other race and ethnicity categories by forcing individuals to choose one. Individuals in the Native Hawaiian, Pacific Islander, American Indian and Alaska Native groups have been disproportionately impacted. While this data can be updated with new entries, it hampers the state's ability to accurately estimate vaccination rates for multiracial, NHPI, and AI/AN categories.

These factors contributed to a period of publicly reported data inaccuracy in the early phase of the pandemic as the state's capacity to report race and ethnicity data failed to meet the expectations of communities, the general public, and media. Insufficient data left the state uncertain of how much COVID-19 was disproportionately impacting certain populations, and community partners, practitioners, and LHJs were not empowered to respond accordingly.

Despite setbacks and lessons learned, many notable improvements are on the horizon. The state stood up California Health and Human Services Agency's Center for Data Insights and Innovation in efforts to improve data sharing and analytics. Surveillance systems are being coded and updated for compliance with new legislation. Labs are now able to transmit disaggregated data for Native Hawaiian, Pacific Islander and Asian groups. The state is collecting more self-reported race and ethnicity data. Additionally, the state is seeking coding solutions for self-reported data and expanding selections for the multiracial population, including meeting with California's largest vaccinators to see how EMRs are coding multiracial.

Data Standards

With much of the discussion revolving around technological solutions, it must be noted that states are in need of standards and policies to inform systems and support best practices. Many hospitals in California are using different standards for race and ethnicity. Health departments and regulated providers need guidance on how to ask race and ethnicity questions, and overall guidance for standard items on all demographic information. At the local level, some LHJs are working with their communities to figure out what standards make sense for their county. Federal guidance is needed on the collection and reporting of race and ethnicity data for the state's growing multiracial population. These are issues the state is grappling with as they move toward the gold standard of self-reported race and ethnicity.

Tribal Data

California's Tribal public health model faces many of the same challenges seen in the other focus states. California has the second largest number of individual federally recognized Tribes within its borders at 109. As a result, staffing and capacity are major barriers and the data exchange process is slow and request-based, with the responsibility of facilitation falling on state Tribal liaisons who must support the various needs of diverse Tribal Nations. There is currently no shared data environment that can be accessed by the state and Tribes, and more staffing is needed to focus specifically on Tribal data. Additionally, more data sharing agreements must be created with California Tribal Epidemiology Center (CTEC) around infectious disease data. Some bright spots involving CTEC's work to address California's AI/AN data inadequacies include the development of a COVID-19 data dashboard using different definitions of AI/AN, and CTEC access to county-level surveillance.

California's LHJs have closer relationships with Tribes generally, although the state meets regularly with CTEC. Bi-monthly data sharing sessions, hosted by the state, are a meaningful venue allowing for the sharing of information with Tribal Nations, and surfacing questions that can inform the wider response team.

Racial misclassification was an issue that California had begun to address pre-pandemic. Misclassification was being further compounded by challenges with the multiracial category, in which AI/AN populations were being systematically erased as they were often being reported in other racial and ethnic categories. The state has updated systems to correct this issue.

Practitioner Recommendations

The following are specific needs and recommendations that were identified by our interviewees representing various roles across the Tribal and governmental public health systems in California:

- Pilot an initiative to change the way race and ethnicity categories are displayed in California to preserve the racial and ethnicity identities of multiracial and multiethnic individuals, and move away from exclusive race and ethnicity categories that must total to 100%

- Technical staffing and funding for improving race and ethnicity data quality that includes DMV data sampling, collecting and applying data from large multi-county health care entities to state databases

- Design a retrospective study to analyze the impact of guidance provided by the state to improve the quality of race and ethnicity input during the vaccination campaign

- Pilot a project to develop a "Master Patient Identifier" to help address Other/Unknown vaccination records by linking to other records with known race/ethnicity information; or a similar project to review the EMR records of individuals with Other/Unknown vaccination records

- Convene a data de-identification workgroup involving CHHS Agency, Pacific Islander and other advocacy groups to create policy that protects privacy and allows for sufficient data disaggregation

- Upgrade technology to help verify demographic information in larger systems that are part of hospital and ambulatory systems

- Invest in improving state data systems and interfaces

- Invest locally as LHJs may look very different and have unique needs compared to the state

MICHIGAN

Although Michigan is currently a majority-white state, the most recent census indicates its Hispanic, Multiracial, Asian, Native Hawaiian and other Pacific Islander populations are growing exponentially. Since 2010, the percentage of individuals identifying as two or more races has increased 176%. Increases in the state's white population may be masking individuals of Arab or Middle Eastern descent, as the Census Bureau currently categorizes residents from these communities as white. The addition of a Middle Eastern and North African (MENA) category was postponed by the Bureau in 2018. Second only to California, Michigan has one of the highest Arab populations in the nation and the highest concentration of Arab Americans is within the metropolitan Detroit area.

The COVID-19 pandemic has exacerbated Michigan's history of public health disinvestment. All of the potential demonstration states have been confronted with the reality of financial hardships at the state and local levels, and face difficult budgeting decisions. Michigan state's health department saw a $237 million decrease in FY22 from its FY21 budget.

Brewing political standoffs over COVID-19 restrictions are also wreaking havoc at the local level, with one county department splitting into two and another threatening to split. These decisions have major implications for funding and capacity in a time where these resources are already stretched thin.

Leadership

In 2020, Michigan's governor signed an Executive Directive declaring racism a public health crisis and prioritized racial equity as an overarching goal in the state's Five-Year Strategic Plan. This goal supports the standardization of REALD (race, ethnicity, language and disability) data across the department, embeds equity into discussions and decision-making, and seeks to identify ongoing infrastructure needs to reduce racial and ethnic disparities. An allotted $8.4 million aims to help decrease health disparities with the use of community navigators, improvements in screening and health data sharing, and enhanced interoperability for systems operated by the Michigan Health Information Network system.

The governor also issued an Executive Order to establish Inclusion and Equity officers in every state department, and established a state-level Coronavirus Task Force on Racial Disparities in response to the disproportionate impact COVID-19 has had on communities of color. A $2.5 million investment also supports the standing up of a REDI (Race, Equity, Diversity, Inclusion) Office.

These specific directives are prioritizing the importance of and need for race and ethnicity data, and creating action and expectations to push forward momentum and widespread impact. Although more education is needed to help staff understand how social determinants of health drive outcomes, investments in equity are creating a culture of awareness amongst the workforce that is being woven into the development of programs and the collection of race and ethnicity data. The state is currently focused on how leadership, data, and training can bolster these efforts.

Data Surveillance Systems

While leadership priorities are promising, system limitations have hindered the state's efforts to provide race and ethnicity data during the pandemic. MDSS, Michigan's primary surveillance system, was positioned to capture race and ethnicity data, however, MCIR, the state's immunization registry, had initial challenges when COVID-19 hit. The state had not been reporting out race and ethnicity immunization data prior to the pandemic, and many issues surfaced when the urgent need arose. Staff needed guidance on how to input data, systems required troubleshooting, and there was minimal capacity for follow up in these scenarios. Additionally, the demand for training needs shifted with different phases of the pandemic. Systems and capacity are major barriers hindering the state's ability to tackle the issues needed to move solutions forward. A promising development is the redesign of MDSS in 2022 which may offer more flexibility in collecting and reporting demographic data.

Data Standards

Data equity has been a large focus of the state for the last decade. Similar to other states, much of what is done with data is federally driven. Although there is not an official, documented policy around minimum standards for the collection of race and ethnicity data, in practice, many state programs are serving the needs of Michigan communities with more granular data. The state collects race and ethnicity for the following populations: American Indian, Alaska Native, Black, Asian and Pacific Islanders, Hispanic, and Arab and Chaldean. In this regard, the state has taken a proactive stance to be responsive to its local communities.

Relationships with advocacy organizations like ACCESS and the Arab and Chaldean Council have been instrumental. Livonia, Michigan is home to the largest population of Arab-identifying individuals. Although the CDC does not consider Arab a racial or ethnic category, the state collects this data locally. Additionally, in the Hispanic, and Asian American and Pacific Islander communities, there are many requests for data specific to their populations, and community relationships have helped inform survey and COVID-19 materials translation. Best practices have been developed to protect the privacy of small populations, and epidemiologists often discuss how and whether data should be collected in these circumstances.

Data Quality

COVID-19 spurred an influx of new laboratories and reporting to the state. The mammoth volume of testing became a barrier to the regular onboarding process the state previously had in place for quality assessment. Lab reporting has been rife with missing information, including race and ethnicity data. In response, the state designed strategies to help fill in the gaps. Contact tracing and case investigation were supplemented with weekly internal data quality scorecards for labs, which were used to measure and communicate progress on data quality. A similar process for local health departments resulted in an added data field for patients who declined to provide race and ethnicity information.

With labs and providers sending incomplete data and patients declining to self-report, state and local health departments have had to create workarounds to find missing information. In addition to using BRFSS and other national surveys to help collect race and ethnicity data, they rotate which populations they oversample every other year to capture data for smaller populations. Social media is a new tool for gathering missing information. With state level data systems numbering in the triple digits, it is not feasible to update all of the agency's technology. However, leveraging data from other systems is a viable solution that can help fill in missing race and ethnicity data. Beyond this data, multiple systems can inform a state vulnerability index that will assist in strategy and response. This kind of resource can be a vital tool in a pandemic when capacity limits blanket outreach.

Tribal Data

Michigan has a history of Executive Directives, dating back to 2001, aimed at recognizing Tribal sovereignty; however, major issues still exist around communication, data sharing, data access, and data governance. This is evidence that legislation is not a standalone solution, and needs action and enforcement to actualize legal intent. The state relies on local health departments to bridge the gap to the needs of local Tribes. However, normative practices that facilitate communication between Tribes and local health jurisdictions breach a 2002 Accord, which upholds federally-recognized Tribes as sovereign Nations and mandates government-to-government relationships. The Accord places Tribal governments on equal footing with Michigan's state government, and outlines protocols and points of contact for consultation between parties at this executive level. State-Tribal agreements are a critical tool for facilitating consultation and collaboration, in addition to the government-to-government agreement between Tribal Nations and the federal government which ultimately upholds Tribal sovereignty.

Tribes in Michigan vary in size and capacity, necessitating different levels of support. State issues with staff capacity and an inability to process an overwhelming amount of data requests in a timely fashion have hindered efforts to serve Tribal Nations. External partners such as the Inter-Tribal Council of Michigan, Inc. (ITCMI) and Michigan Public Health Institute (MPHI) have been engaged as intermediaries to provide support like technical assistance. Both partners were instrumental in conducting the 2017 Tribal Behavioral Risk Factor Survey (NaBRFS) which provided meaningful data for Tribes and the state, and was made possible with funding from the state's Office of Equity and Minority Health (OEMH). However, there are still major obstacles like slow responses to data requests impeding the ability of Tribes to make data informed decisions in a responsive manner. The COVID-19 pandemic has elucidated how critical of an issue timely data is when lives and the survival of communities are at stake. Privacy concerns for Tribes with small populations are a concern stateside, and this highlights the issue of data governance. Sovereign Tribal Nations should have ultimate ownership of their data, regardless of the point of collection and small counts.

Governor Whitmer's Executive Directive 2019-17 is in effect as MDHHS has provided mandatory training to its 14,000 employees. Three live and recorded sessions in early 2022 covered the Executive Directive requirements, the impact and long-lasting effects of historical trauma on Tribes, and emphasized the uniqueness of Tribal sovereignty and how this status should shape the work of MDHHS. Over 11,000 employees viewed the sessions live and 400 questions were submitted after the first session alone.

Dovetailing this training is MDHHS' announcement to Tribal leaders in February 2022 that the agency has initiated a department-wide review of:

- all places where MDHHS is collecting data relevant to Tribes and Indigenous populations, and how that data is collected, reported and shared publicly;

- how data can currently be shared with Tribes within existing laws, e.g., HIPAA, Michigan Child Protection Act;

- the data systems in place that house Tribal data and whether or not they are capable of interfacing with Tribal systems (this step is intended to improve data sharing with Tribes); and

- an exploration of any laws or rules in place that currently inhibit the open sharing of data with Tribes; how they can work better within the ones that cannot be changed, i.e., federal laws; and if they need to initiate legislative changes at the state level.

A Tribal Health Directors Association of Michigan meeting is slated to take place in April 2022 for MDHHS to consult with Tribes on the types of data they need. This meeting will identify where MDHHS could have done better in the context of COVID-19, but will also address the areas the pandemic illuminated where MDHHS can improve more broadly.

Practitioner Recommendations

The following are specific needs and recommendations that were identified by our interviewees representing various roles across the Tribal and governmental public health surveillance systems in Michigan:

- Assess current systems to analyze which ones can collect race and ethnicty data and why

- Analyze and compare systems across the nation to surface best practices and standards for collection and reporting

- Upgrade systems for flexibility as forms are static and customizable fields are needed

- Upgrade systems to capture how self-reported data is collected and how questions are being asked; i.e., was it the patient actually self-reporting or the reporter guessing

- Identify and improve upon specific barriers to Tribes receiving their data in a timely fashion

NEVADA

Nevada is considered a minority-majority state with increasing racial and ethnic diversity. With a shift that is changing the demographic picture of the state comes the need to further examine health inequities and create a statewide plan to achieve health equity. Nevada's leadership is not currently focused on data disaggregation, and the state will continue to fall behind if they do not address the growing need for more granular race and ethnicity data.

Nevada relies heavily on federal funding although it ranks 45th in the nation in federal grants received. Nevada public health funding ranks 49th in the nation at $72 per capita (tied with Wisconsin), compared to a high of $449 in Alaska and the national average of $116 per capita. State public health is vastly underfunded and under-resourced for public health preparedness. These funding realities have compounded the state's inability to respond effectively in a public health emergency, as illustrated by its early COVID-19 response. Nevada has been one of the hardest hit states by the pandemic, due to its economy's reliance on tourism. As the pandemic progresses, state and local health agencies may continue to face budget challenges for the foreseeable future.

Data Surveillance Systems

Nevada's initial surveillance response to the COVID-19 pandemic was severely inadequate and the state continues to struggle, mainly due to an outdated surveillance system, National Electronic Disease Surveillance System (NEDSS) Base System (NBS). NBS is a NEDSS compatible information system designed to facilitate public health investigation workflow processes and supports the secure exchange of reportable data. NBS is not set up to collect disaggregated race and ethnicity data beyond OMB standards. Further, race and ethnicity are not required fields to be able to move through the system. Beyond these limitations, users have been constrained by the slowness of NBS, and the system crashing, freezing and logging users out. Issues with NBS have been exacerbated in a frenzied pandemic environment where data is needed in real time. While 20 states and 5 territories currently use NBS, Nevada is the only one among the five we examined.

Data modernization is a critical need. The state is currently paying for and using two separate and siloed surveillance systems for reportable data, which has further strained staff who are already stretched thin. Time has been drained on duplicative efforts and the transfer of files between systems. Pandemic focused priorities have not allowed the state's health agencies the space to pause and reflect on current and future priorities, or needs around the minimum collection of race and ethnicity data, let alone more granular data. COVID-19 has illuminated the public's desire for customized data, yet data can only be as good as systems allow. The state is implementing and currently moving toward the use of EpiTrax, which has greater capabilities than NBS and will collect surveillance data on most diseases.

Bright Spots

The reorganization of state offices to support Nevada's data infrastructure is a bright spot, but with time-limited and restricted COVID-19 funding, they may need to wind down some of their current efforts as quickly as they have ramped up. The state has shown a recent interest in data equity, however, work is primarily focused on SOGI (sexual orientation and gender identity) data, and not race and ethnicity data. Legislation is a tool that can help push momentum forward, and can be utilized more strategically with the addition of an overall vision and plan around data disaggregation. Promising work includes the building up of a data management infrastructure, leveraging external partnerships such as UNLV to help fill gaps in race and ethnicity data, and advocacy work to further disaggregate the Asian and Pacific Islander category.

Tribal Data

Tribal efforts in Nevada are complicated by a lack of dedicated staff beyond state Tribal liaisons, and formal mechanisms in place to facilitate communication and data sharing. Tribes have access to NBS, but it is unclear how extensively they are using the state's surveillance system and challenges with it have been noted. The strength of relationships between Tribal Nations and the state are regional and often depend on individual county relationships with Tribes. Communication has suffered from turnover at the Tribal and state leadership level. Data requests are currently handled piecemeal on an individual Tribe basis, with data sharing agreements on hold until relationships are cultivated further.

Practitioner Recommendations

The following are specific needs and recommendations that were identified by our interviewees representing various roles across the Tribal and governmental public health surveillance systems in Nevada:

- Systems need coding for accurate American Indian and Alaska Native selections
- A robust health equity strategy is needed as they are trending toward becoming a minority majority state
- Standardized equity measures could be used to assess where Nevada is currently and where the state would like to go

NEW YORK

The most recent census results reveal New York has many complex issues to consider around race and ethnicity data. The state is becoming increasingly racially and ethnically diverse, with its Hispanic, Asian and Multiracial populations growing in line with national trends. The state's diversity index increased to 65.8% in the last decade, the seventh highest index in the country (tied with New Jersey). New York's white population has declined in all but five counties.

New York's Executive Budget has undergone cuts to public health in current and recent years. These budget cuts have resulted in a continual decrease in staff and public health programming at the state and local levels. New York's shrinking public health infrastructure comes at a time when states should be ramping up efforts in anticipation of a greater need for emergency preparedness, such as in the case of the COVID-19 pandemic, and for devising strategies to tackle the many needs of its growing and increasingly diverse population.

COVID-19 and Race and Ethnicity Data

In the spring of 2020, the world watched as New York became the epicenter of the COVID-19 pandemic and its health and public health systems struggled to respond. Two years later, the state is still overburdened by data collection and reporting processes. Victim to its size and mechanics, siloed systems, siloed data sources and siloed programs plague one of the largest public health systems in the nation. New York has 62 local health departments, and NYC's health department alone is larger than some state health departments.

Hospitals and labs are a major source of reportable case data, yet providers were overrun early on in the pandemic with very little capacity to ensure complete or accurate patient data. Like other states, it became clear rather quickly that an effective response strategy required demographic information, including race and ethnicity. Discussions around data improvements became a weekly theme that ultimately led to an online COVID-19 data dashboard. While data collection processes have not changed, communication has improved internally and externally, and there is now a more concerted and focused effort to ensure the state is collecting race and ethnicity data.

Pre-COVID, a task force was established focusing on the standardization of data collection and reporting for systems across the state. The initial groundwork for these efforts has been laid, but conversations need to continue. The state is in the early stages of discussions about standards that will be reflective of state populations and national standards, and the need for an internal assessment of current data collection practices that may need to change. The pandemic has since shifted state priorities and staff have been pulled into the COVID-19 response. It will require a concentrated effort to break down silos and coordinate a statewide effort to standardize, collect and report more disaggregated race and ethnicity data, and this largely depends on state commissioner priorities.

Data Modernization

In one local health department, data modernization efforts began long before COVID-19. Health IT was identified as an area of inequitable capacity between health care providers in affluent communities compared to low-income communities. EMRs were targeted as the link that could be a game changer for the future of health and health IT; helping to connect data sources and level the playing field so that low-income communities would not be left behind. As such, there was an intentional effort to work with providers that serve low-income communities to adopt EMRs. Building on their EMR expansion, the health department then focused on data quality improvement and partnering with RHIOs (regional health information organizations) to strengthen the data capacity of the region. ONC guidelines and incentives were also leveraged to prioritize race and ethnicity data improvements. These efforts led to an ecosystem that has enabled race and ethnicity data to be well documented in the service area (e.g., upwards of 93-95% race and ethnicity data completion in a predominant EMR) and positioning the department to be prepared to speak to specific community needs when COVID-19 hit. In this specific case, the health department's data modernization efforts improved race and ethnicity surveillance data because addressing health equity was a priority from the start.

Policy

On December 22, 2021 with relatively little press coverage, New York's new Governor, Kathy Hochul, signed bill A6896A/S6639A requiring state departments to disaggregate data for Asian and Pacific Islander groups that had been previously aggregated. The bill, which had been introduced several times since 2011, was last vetoed in 2019 by Andrew Cuomo. Its passage will mandate state agencies to separate categories for Chinese, Japanese, Filipino, Korean, Vietnamese, Indian, Laotian, Cambodian, Bangladeshi and Hmong populations. Additionally, Pacific Islander populations will be further disaggregated to recognize Native Hawaiians, Guamanians, Chamorros and Samoans. The long-awaited victory comes for community stakeholders and advocacy groups like CACF (Coalition for Asian American Children + Families) that are raising awareness about the role data plays in determining resources and equitable opportunities.

Although the bill has been signed into law, it remains to be seen how long it will take for effective implementation which requires resource allocation. Systems need new coding and updating, and the new requirements will have a major impact on the collection and reporting of data by regulated providers—i.e., hospitals, health care providers, coroners, etc. For programs that report on race and ethnicity data, the shift will require developing and implementing new protocols that consider how the data will be used, reporting requirements and quality standards, and staffing capacity and workflows. Further, while data disaggregation has many benefits for traditionally underrepresented communities, it introduces privacy issues for smaller populations, and the statistical challenge of identifying patterns in more granular data. A number of the state's data collection hubs currently collect disaggregated data, which is then aggregated for use. In addition to crafting a more comprehensive aggregation plan, many conversations and decisions still need to take place to appropriately comply with the new legislation.

The signing of New York's data disaggregation bill comes on the heels of a major health report released by the NYC health department on December 10, 2021. The report, entitled Health of Asians and Pacific Islanders in New York City, takes a deep dive into health disparities that have been masked by an overarching Asian and Pacific Islander (API) category and accompanying "model minority" myth. Bringing to light the health of distinct ethnic groups is a step toward removing the barriers to better health and wellness for communities that have been obscured by the broad API category.

In 2015, a need for internal reform sparked movement in racial equity work and data equity in a local health department. Change was seeded with workgroups focused on racial justice and blossomed in 2018 when a cross-agency workgroup was created to reform data with a racial equity lens. The workgroup examined the life cycle of surveillance data, from conceptualization to reporting, and explored frameworks and ways communities are engaged throughout this process. Several guidelines were proposed and approved in 2019, including recommendations to make the workgroup permanent within the agency and to begin a project around data disaggregation. The project convened internal focus groups to discuss data disaggregation, which revealed the issue is more complicated when the entire life cycle of data is considered. Project findings have informed recommendations from the workgroup. Broad principles for undertaking data disaggregation include:

- the inclusion of individuals and communities whose information is being collected and represented at every stage, from conceptualization to communication and dissemination;

- creating a community of practice to facilitate peer-to-peer learning;

- actively shifting who is invited to the table for conversations around data; looking beyond data analysts to non-data experts; and

- committing internally to undo oppressive power structures alongside the work of data reform.

Tribal Data

A history of past and current harm has limited relations between Tribes and the State of New York. High level barriers at the state level include capacity, communication, ruralness of Tribes, the complexity of laws and customs governing different Tribes, and the lack of legislation upholding a government-to-government relationship between the state and Tribal Nations. The state currently works directly with individual Tribal Councils and there are no formal mechanisms or established agreements for data sharing or data access. This could be due to an attitude of deference on the part of the state that seeks to honor Tribal sovereignty but misses the opportunity to actively forge necessary formal government-to-government agreements. There is limited bidirectional data sharing occurring, i.e., data received from the state and data sent to the state. A third party is needed to convene relevant parties and facilitate Tribally-led data sharing between Tribes and the state. USET, the regional TEC, along with the National Indian Health Board (NIHB) and the National Congress of American Indians (NCAI), are organizations that have supported data sharing with Tribes and can potentially provide further support on the issues. There is a need to discuss solutions to existing barriers which include:

- a lack of dedicated state staff supporting the needs of Tribes beyond a single contact whose overall responsibilities may limit this focus;

- the need to establish a more formal working relationship between USET and the state;

- state side bureaucratic barriers to data access for Tribes; and

- ongoing education for the state on Tribal sovereignty, including federal trust responsibility, treaty obligations, and data sovereignty.

Data quality is also a major issue. In particular, census data has been inaccurate, grossly undercounting members of Tribal Nations. Overall, the quality of data is poor, and due to the lack of formal mechanisms, improvements are implemented in a piecemeal fashion by programmatic issues, e.g., alcohol abuse, mental health treatment, or regular check-ups. As a result, the focus remains on the delivery of basic public health services and not the improvement of data quality, data access, or data exchange.

Practitioner Recommendations

The following are specific needs and recommendations that were identified by our interviewees representing various roles across the Tribal and governmental public health surveillance systems in New York:

- Support for the TEC (USET) to spearhead and facilitate data sharing between the state and Tribes

- Set up a data sharing system for the Tribal health centers within the state

- Review and update state laws as needed to address systemic issues and processes around data sharing for Tribal data sovereignty

- Need dedicated teams solely focused on centralizing data

- Continue pre-COVID task force work to standardize how race and ethnicity data is collected and reported in systems across the state

- Support qualitative data methods of collecting lived experiences, such as ethnography

- Pilot studies for radical public health work that explore identities beyond categories

- Support community-based participatory research (CBPR) based in organizing

- Guidance and frameworks are needed on community involvement and data

- Provide resources to pay community members for freely sharing their lived experiences

- Focus on Qualified Entities/RHIOs, as they collect and exchange information across multiple systems and can be incentivized

- Advocate for federal government to set restrictions or incentives on EMRs as part of their certification

- Create strategies that will widen the data stakeholder audience to include the general public

- RWJF can use its influence to commit to and advance the field by deconstructing and reimagining demographic data that reflects data equity

WASHINGTON

The recent census indicates Washington is growing increasingly diverse, with results showing the largest decrease in the nation in its non-Hispanic white population (down 8.7%), and notable increases in its Hispanic and Asian populations. The state's diversity index saw a 10 percent increase in points from 2010 to 2020, with a leap from 45.4% to 55.9%. Over a third of the state is now composed of minority groups.

Washington's decentralized public health system encompasses the State Board of Health, the Department of Health, 35 local health jurisdictions, 29 sovereign Tribal Nations, and 2 Urban Indian health programs, which serve the state's 7,766,925 residents.

Washington's public health infrastructure has been on the decline for three decades, with support for core public health services decreasing despite a widening gap in health disparities and growing number of outbreaks. While the state is currently focused on COVID-19 efforts, leadership seeks to position the state for a brighter future with strategic investments in data modernization and health equity.

Leadership

Washington has forward thinking leadership in place at the state and local levels with the foresight to see where issues are currently and where potential issues may arise that need systems and solutions in place. The state's new Secretary of Health has a background in health equity work and has been recognized for leadership in engagement and innovation. The state is tackling issues head on and having the necessary, difficult philosophical discussions around race and ethnicity, including addressing how to handle data reflecting their growing minority and multiracial populations. Washington is laying the foundation to support data disaggregation with its efforts to institutionalize equity, as evidenced by the creation of an Office of Equity and cross-agency equity teams, and embedding an equity lens into their approach and work. Within this framework lies an opportunity to align departmental equity work with best practices and standards across all Washington agencies.

Data Modernization and COVID-19

Prior to the COVID-19 pandemic, Washington recognized the need for more granular race and ethnicity data and engaged with communities to begin the work around data disaggregation. As such, some surveillance systems were capturing race and ethnicity data when the pandemic hit. Still, the department has struggled with missing data, and many systems have been designed with siloed grant funding, creating interoperability issues that have exacerbated capacity constraints. Data sharing is restricted by siloed and often outdated statutes and rules governing each of the state's approximate 50 surveillance systems, and these legal and regulatory challenges are a barrier to leveraging data for health equity. Efforts are underway to modernize systems in regards to access and sharing, privacy protections, security, and storage.

In response to the COVID-19 pandemic, the state stood up a new Office of Public Health Outbreak Coordination, Informatics, and Surveillance (PHOCIS), an innovative data infrastructure model, to coordinate a robust and coordinated statewide response to COVID-19 and future outbreaks. PHOCIS has oversight of informatics and surveillance activities, including electronic laboratory reporting (ELR) and electronic case reporting (ECR). These activities also support notifiable conditions reporting, case and contact investigation, and syndromic surveillance.

Federal COVID-19 funding and state funding have been directed to systems-based solutions and workarounds, such as a modular, flexible, cloud-based, shared analytic environment in the form of a master person index (MPI), which will enable linkages across data sources. The MPI has been developed with input from state and local partners, and Tribal governments. However, it is critical to note that most COVID-19 funding sources are set to run out in the middle of Washington's 2021-23 biennium, and a lack of continued funding will hinder the implementation of data modernization efforts.

Community Advocacy and Engagement

Washington has active racial and ethnic community groups that inform policy and decision-making, including a network of advocacy organizations that promote data disaggregation. The state's Healthy Youth Survey expanded the collection of API ethnicities for students in 2016, and following suit, the state's health department recently separated Asian, Native Hawaiian, Pacific Islander, and MENA populations into distinct categories.

There is recognition that Washington is moving into uncharted territory, along with the rest of the nation, where the existence of a fast growing multiracial population negates the ability to have reporting totals that equal 100%. In the absence of federal guidance, they are introducing alternate and flexible ways of collection at the local level, using self-report as the gold standard, and reporting totals that do not equal 100%. In addition to explicit questioning of the meaningfulness of a blanket multiracial category, the state is having more general philosophical discussions around race and ethnicity data:

- Who does it serve to have a blanket multiracial category?

- To what end does a multiracial category help public health understand what is happening in specific communities?

- What are we standardizing to?

- The presence of data doesn't equate to action. What are leaders going to do with it?

Policy

Washington's adoption of rules requiring the reporting of race and ethnicity notifiable conditions data was a major effort that was four years in the making. The Notifiable Conditions rule requires health care facilities, providers, laboratories, and local health jurisdictions to collect patient race, ethnicity and language data. The requirement was originally slated to go into effect January 31, 2022, but has been pushed back to January 31, 2023 to allow the Department of Health and regulated entities ample time to prepare for compliance. The new effective date for the Notifiable Conditions rule aligns with implementation of E2SHB 1272 (2021), a bill requiring hospitals to collect and report extensive patient demographic information, including race, ethnicity, gender identity, sexual orientation, preferred language, disability status, and zip code. While this is promising progress, health departments, providers and laboratories must adjust systems and workflows to be in alignment, and success ultimately relies on the compliance of partners.

The state's engagement of community stakeholders in the rulemaking process serves as a model for similar public health rulemaking. Community engagement requires tremendous legwork on the front end, but when relationships are cultivated properly, can enable a more swift, comprehensive and effective provision of basic public health and response in public health emergencies. There is a genuine desire at the state and local levels to engage communities in a respectful and fair manner, with the sobering reality and understanding that all needs may not be met equally and adequately.

Tribal Data

Washington's legislative efforts regarding Tribal sovereignty once again demonstrate the need for action in tandem with legislation, as evidenced by the state's Centennial Accord. The Accord is a treaty that was signed by the state's federally-recognized Tribal Nations and the State of Washington in 1989 recognizing the sovereignty of Tribal Nations, and executes government-to-government relationships. As evidenced in a 1999 report, Challenges to Relationships Between the State of Washington and Washington Tribes, issues that were of concern more than two decades ago continue to persist, including awareness of Tribal sovereignty, communication, turnover in leadership and staffing in Tribal Nations and in the state health department, the complexity of legal issues, the need for more dedicated points of contact, and a lack of data sharing agreements.

In Washington, there are also Tribal concerns about disaggregated data revealing Tribal affiliation, which sometimes lies in stark contrast to other community groups that want granular data to understand their health outcomes. The state realizes this presents a unique challenge and is working through mitigation strategies with Tribal Nations, and through its data modernization efforts. As a result, the state is exploring potential solutions such as educating providers on privacy issues upfront and restricting data downstream in systems.

Despite these barriers, Washington has the beginnings of the basic infrastructure in place to support the various health needs of Tribes. The state is currently in consultation with Tribes and Tribal partners for the expansion of data sharing agreements. Data access efforts include piloting read and write access with Tribes in WDRS, the state's disease reporting system. The state is also consulting with Tribal Nations to align Tribal public health with the state's public health model. There is acknowledgement of a runway for improvement, even as Washington leads the other four focus states in terms of Tribal engagement, collaboration, and support.

Practitioner Recommendations

The following are specific needs and recommendations that were identified by our interviewees representing various roles across the Tribal and governmental public health surveillance systems in Washington:

- Provide local health jurisdictions access to federal data sets, e.g., Medicare data

- Assist in creating a plan for a data, legislative, legal and regulatory modernization initiative

- Support to complete core infrastructure upgrades so systems can collect and report race and ethnicity data

- Upgrade infrastructure for national standardization beyond cloud analytic environment and Master Person Index that is embracing newer HL7 standards

- Guidance on how to think about and present race and ethnicity in the context of a research question, especially for the multiracial population, with investments in solutions that partner with community-based organizations

- Grant flexibility in what the state can do with federally funded surveys that are relied on as part of routine public health assessment work; funding is needed to add state tailored modules

Commentary on Future Directions

Conclusions drawn from our findings should take into account the parameters of our project scope and methodological limitations. While we consulted with experts and sources with a national purview, the bulk of our research relied on interviews with practitioners in RWJF's five select states. All of the five states have a decentralized public health structure with the exception of Nevada which is hybrid. What we heard about the logistical challenges and opportunities for data disaggregation is biased towards these contexts, and may not be representative of the views across states and Tribal Nations. We may be missing nuance and outright difference that is important to consider to advance data equity in centralized or other hybrid structures. We also acknowledge that the vast majority of Indian Country is not co-located among the five select states. There is potential to learn more about what works to support Tribal data sovereignty in places where there are more and larger Tribes. We also did not focus on any of the U.S. territories (i.e., American Samoa, Guam, Northern Mariana Islands, Puerto Rico, and U.S. Virgin Islands) to examine how issues related to data equity and systems barriers may play out in these specific contexts. This exclusion reflects the inequitable colonial relationship between the U.S. and the territories that are subject to a status that is neither sovereign nor positioned to have the full rights and representation afforded to states. To fully embrace the potential for data equity, we must further examine aspects of systems in geographies that were beyond the scope of this project.

We directly asked practitioners what they thought is needed for data equity. Their ideas about solutions are integrated into earlier sections of this report. We also heard them asking bigger and thought-provoking questions that are crucial to grapple with:

- While we are striving for better race and ethnicity data, how does this fit with getting better at measuring structural racism?

- How do we create data systems and practices that allow for the inevitable and continual evolution of racial and ethnic identity while also meeting criteria for sound statistical analyses—especially as multiracial populations grow and the need to understand intersectional identities that are important for equity expands?

- Laboratory case reports are a major source for understanding race and ethnicity in public health surveillance data, but is this the best place to rely on for this kind of data?

- How do we best make meaning of disaggregated data that matters for health equity? How and who is best to interpret and translate this data for audiences (e.g., policymakers and the general public) where disaggregated categories may be new and not well understood?

We do not have the answers to these questions. Their answers, however, can inform where data equity fits into RWJF's broader theory of how measurement can advance health equity. What we can share is our own thoughts about addressing data equity in governmental public health surveillance based on what we heard from the field.

Our nation's public health system is widely varied, complex, and rife with barriers to data equity. The separate and severely under-resourced Tribal public health system adds another layer of complexity. Investment in strengthening resources and capacity to address any barrier across the systems has the potential to make some headway. To be truly transformational, however, a multi-pronged strategy is necessary. This strategy could benefit from leadership engagement across many types of stakeholders and should encompass a range of strategic levers.

Building Capacity for Community Engagement and Policy Advocacy on Data Equity Issues

An aspect of data equity hinges on the creation of meaningful race and ethnicity categories that are recognized by and reflect the communities they intend to capture. Creating race and ethnicity categories that communities identify with improves the face validity of measurements and allows communities to advocate for access to and utilize their own data. Capacity building may require organizing Tribal, racial and ethnic communities to demand progress on data equity issues. Equally critical, however, is bolstering the capacity that is needed within governmental public health to better understand how to conduct respectful, authentic, and productive Tribal, racial and ethnic community engagement. Strengthening the relationships between Tribal, racial and ethnic communities and governmental public health has the potential to create the political will necessary for changing policies, regulations, and practices that can improve data equity. It is not enough to merely establish these relationships. There must be ongoing consultation to capture the ever-evolving nature of communities and politics of racial and ethnic identity. Governmental public health may also benefit by having an activated base of support that can advocate not only for its community needs but also the resources that are necessary for agencies to provide quality public health writ large.

Cultivating, Convening, and Aligning Leadership on Data Equity Improvement Strategies, Policies, Regulations, and Practices

Political will for data equity can also be cultivated among leadership. For systems-level change, leadership across multiple levels of jurisdiction (i.e.,Tribal, federal, state, and local) and influential institutions (e.g., NCQA) can be engaged to create a shared understanding of data equity principles, strategies and tactics, supportive practices, and why it matters. We heard the need for movement to be cultivated in both a top-down and bottom-up fashion. At the national-level, treaties and laws that mandate Tribal sovereignty need to be honored and upheld. More public health law intervention and communications are needed to clarify the public health authority that Tribes and TECs possess which preempts any contradictory state or local policy. Further, federal agencies that govern national public health surveillance activities need to coordinate and align on race and ethnicity data value sets, standards, and requirements. These agencies are also in position to create incentives or penalties that motivate data quality improvements. While national-level changes may have systems wide effects, implementing them will be no easy undertaking. Federal agencies are burdened with layers of bureaucracy and strategic initiatives can change at the whim of political administrations. Therefore, the nimbleness of Tribal, state, and local jurisdiction leaders is an advantage for testing out and adopting data equity approaches, building the case for data equity, and creating bottom-up change.

Providing Widespread Training on Tribal Data Sovereignty and the Value of REaL Data

We heard repeatedly that the data Tribes, TECs, and public health departments have is only as good as the quality of the data they receive, if they receive it at all. Regulated providers could benefit from training staff on best practices for collecting self-report REaL data, why it is valuable, and the importance of complete and accurate data collection and provision. Training is a need that also extends beyond data providers. For Tribal data sovereignty, this need translates to training across systems for all entities that capture Tribal public health data, i.e., local IHS clinics, local health departments, state health departments and federal agencies. Training should emphasize how and why Tribes have a unique political status with public health authority giving them the right to access identifiable data in the same and timely manner as any other public health authority. This public authority is also extended to TECs and should be included in any educational initiatives that seek to raise awareness on Tribal data sovereignty.

Demonstrating, Sharing and Scaling Measures that Improve Tribal Data Sovereignty, Data Modernization, and REaL Data Quality

Systems-level change requires large-scale coordination and alignment which can be resource and time-intensive. Opportunities exist to seed and leverage existing projects supporting data equity related to Tribal data sovereignty, data modernization efforts, and improving REaL data quality and their relevant data systems. Several examples of the kinds of projects that could be funded are detailed in the state profiles. A community of practice could be developed to foster the exchange of ideas, be a resource to identify what is working, and inform directions for future investments. In addition, Tribal and racial and ethnic community engagement are imperative for equity and any demonstration projects that include Tribal data should be led by Tribes.

To move forward, however, we must first acknowledge that our public health systems operate within a context that is structured to incentivize racialized capitalism. It is no surprise that the public health sector is positioned as a safety net but has data systems that are outdated, underfunded, and under-resourced, rendering them inadequate for upholding Tribal data sovereignty and producing quality race and ethnicity data. Any efforts to change this requires us first to interrogate the reasons why people have been racialized. Additionally, we must examine the perverse cultural, institutional, and financial incentives that exist to maintain the racial caste, and why the measurement of its ill effects receives little attention. Understanding this context is fundamental to pursuing transformational change within and beyond public health.

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