

Catalyze Transformative Shifts in Utilizing Data

SUPPORTING COMMUNITIES AND LOCAL PUBLIC HEALTH
DEPARTMENTS DURING COVID-19 AND BEYOND —
A ROADMAP FOR EQUITABLE AND TRANSFORMATIVE CHANGE



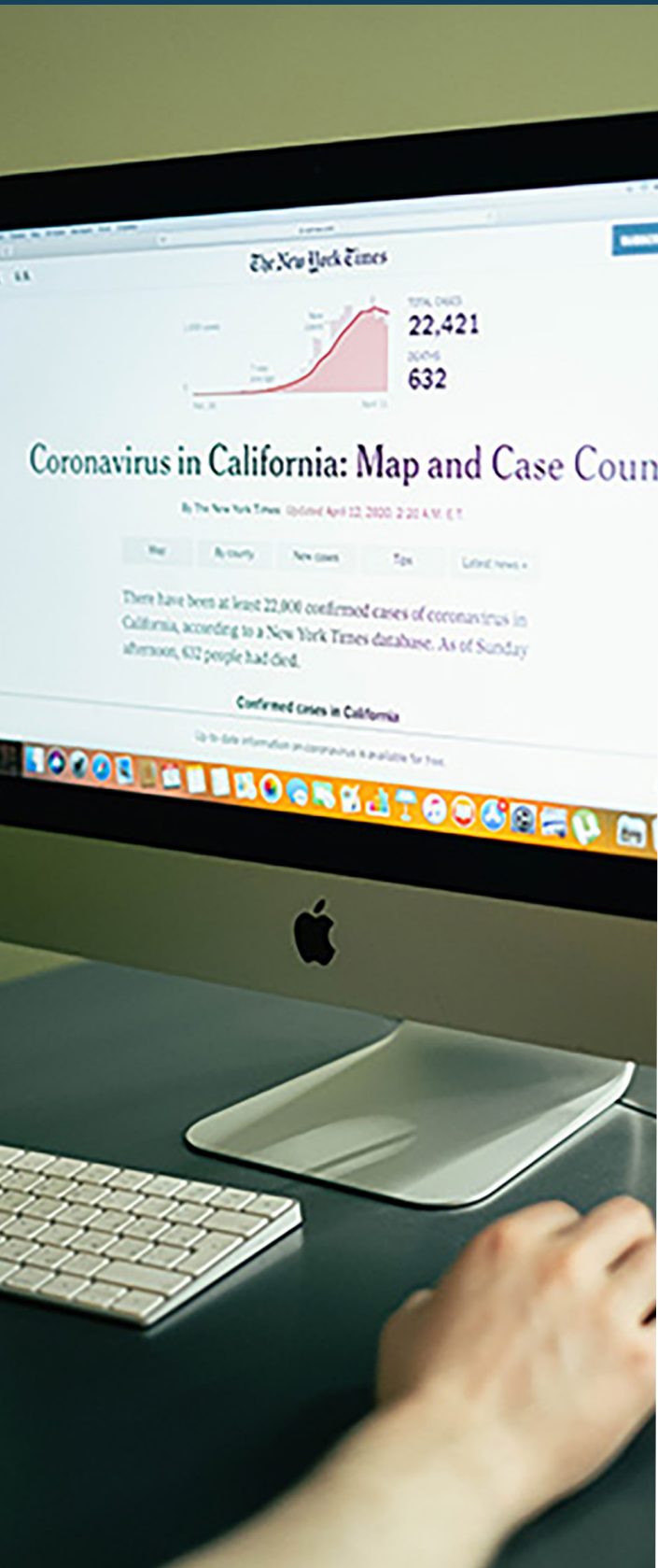
Public Health Alliance[™]
OF SOUTHERN CALIFORNIA

JULY 2022

The Public Health Alliance is fiscally sponsored by the Public Health Institute



This document is one section of the [Supporting Communities and Local Public Health Departments During COVID-19 and Beyond - A Roadmap for Equitable and Transformative Change](#) report drafted by the Public Health Alliance of Southern California that includes policy, program, and resource recommendations to ensure that local public health departments are adequately prepared to support communities most vulnerable to the health and socioeconomic impacts of COVID-19 as well as future public health emergencies.



RECOMMENDATIONS

- ▶ Support Development of a Modern Public Health Data Infrastructure
- ▶ Integrate Local Public Health Department Stakeholders in State Governance of Data for Policies, Practices, and Metrics
- ▶ Institute “Health Equity Metrics” Across State and Local Government Operations and Investments
- ▶ Expand and Improve Collection of Demographic Data
- ▶ Standardize Data Practices Statewide, in Collaboration with Local Public Health Departments, to More Effectively Track Disparities
- ▶ Support Comprehensive and Transparent Public Reporting of Impact Data
- ▶ Develop a Unified, Bidirectional Statewide (HIE) with Interoperability between State and Local Public Health Departments, and Healthcare and Hospital Systems



OVERVIEW

Over the last year, several data challenges have affected the ability of the State and local public health departments to track and respond to the equity impacts of the COVID-19 pandemic.

Without data – collected, analyzed, and publicly reported in close partnership with local public health departments – it is impossible to track the equity impacts of COVID-19. To assess these impacts, data must be collected that reflect key demographic characteristics linked to health inequities, including race/ethnicity, gender, and sexual orientation. It is important to identify population-specific challenges, and design data collection and reporting accordingly. For example, race/ethnicity data are frequently missing, and when not missing, misclassification is a persistent issue. Without processes to address these problems and others like it, impacts to specific groups may not be captured accurately.

Some impacts are tied to community factors, such as household income, housing crowding, and transportation access, in addition to or instead of demographic ones. It is equally important to collect and report data at the smallest possible geography, while adhering to reasonable standards of privacy. A balance must be struck between actionable data and the risk of individual identification.

To establish and keep the public trust, alignment of State and local data reporting is necessary. A State commitment to transparency and collaboration in the development of data collection, analysis, and reporting processes, as well as in the creation of tracking metrics tied to direct impacts (including funding and other resources) on jurisdictions are crucial to this end. This commitment could take the form of policies mandating the collection of key demographic measures, creation of formalized processes for developing metrics that include input from local public health departments, and timely, complete publishing of methodologies used to track health outcomes or calculate metrics.

The recommendations in this chapter describe improvements to existing data practices, towards development of systems that capture health inequities and prioritize the response to the most affected communities.

CHALLENGES

1. Missing, incomplete, or inaccurate demographic data – particularly by race/ethnicity, alone or as a stratification variable for other outcomes – impede monitoring and addressing equity impacts
2. Outdated and inflexible data systems paired with a lack of data standards failed to meet demands of COVID-19 response
3. Missing or incomplete methodology provided for State reopening and reporting metrics
4. Communicating data to communities

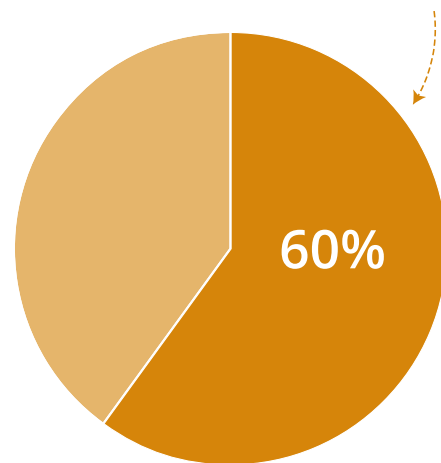
1. Missing, incomplete, or inaccurate demographic data – particularly by race/ethnicity, alone or as a stratification variable for other outcomes – impede monitoring and addressing equity impacts

There have been ongoing issues of missing data, specifically related to demographic characteristics, and particularly from testing, lab reports, and point-of-care. State and local public health departments have internalized these reporting issues, when it is in fact a result of incomplete collection or pass-through of data from labs, clinics, and other healthcare providers. Put simply by one respondent to the LHD Data Survey (December 2020), “race/ethnicity and SOGI [sexual orientation and gender identity] are a challenge to collect.” Even with State collection mandates, LHD staff during one California Conference of Local Public Health Data Managers and Epidemiologists (CCLHDME) meeting reported that providers commonly input “other” or “unknown” for race and/or ethnicity:

“As long as healthcare can report ‘unknown race/unknown ethnicity’ we won’t get good data – and can’t track if vaccinations are being equitably distributed.” LHD respondent

In September 2020, during a California Association of Communicable Disease Controllers (CACDC) meeting, one jurisdiction reported that the “unknown” and “other” categories selected for race comprised nearly 60% of their reports.

MORE THAN HALF OF PROVIDER REPORTS SELECTED “UNKNOWN” OR “OTHER” FOR RACE/ETHNICITY



During periods of surging COVID-19 infections, respondents to the LHD Data Survey noted that the “unprecedented volume of cases and lab results” contributes to challenges in data collection – and “reaching enough cases to collect race/ethnicity is especially challenging in regards to health equity.” One jurisdiction wrote that this is “frustrating... as [staff] attempt to prepare a comprehensive report on disparities suffered in some zip codes.”



Missing data only represents the most visible challenge. Race and/or ethnicity misclassification, telegraphed through the preponderance of the “other” category in demographic tracking, makes accurately capturing inequities in COVID-19 metrics difficult, if not impossible. Smaller communities, such as Native Hawaiians and other Pacific Islanders (NHPI), and American Indians and Alaska Natives (AI/AN), are particularly impacted either in their undercounting (when they are systematically misclassified into other groups) or in potential exaggeration (when non-NHPI or AI/AN individuals are classified as such) of disparities. In either case, bias from those inputting data interferes with being able to accurately measure the impacts on these communities.

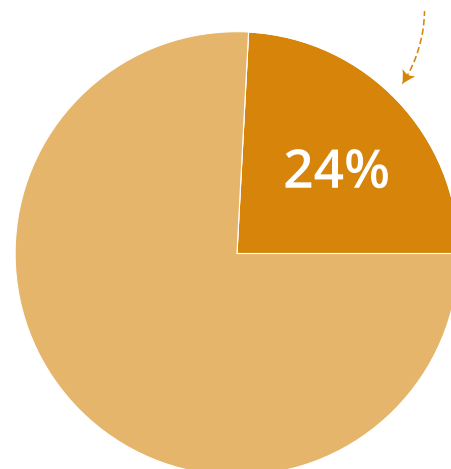
Over the course of the pandemic, and based on ongoing monitoring of publicly reported COVID-19 data by the Public Health Alliance, many jurisdictions have experienced this issue. In a late May 2020 CCLHDME meeting, LHD epidemiologists openly discussed the specific impacts in their jurisdiction. Many noted that there have been differences between what appears in the State’s reportable disease surveillance system for race/ethnicity compared to what is reported on death certificates. Because vetting of data on death certificates is more thorough than vetting of the data collected of cases, it is surmised that data on cases may be most affected by this bias compared to data on deaths. There have been periodic re-classifications of NHPI, Other, and AI/AN cases and deaths on local public health department data dashboards; but it is unclear how reconciliation of data discrepancies is occurring, whether in a systematic way or a piecemeal fashion. One Bay Area county reported that they resorted to calling people to clarify. This solution may work when case/death rates are low, but impossible during surges without significant increases in LHD staff capacity.

Underlining the challenges faced by AI/AN communities, the Urban Indian Health Institute published a [report card assessing the quality of](#)

[each state’s COVID-19 reporting](#). Citing a surfeit of incomplete or missing race/ethnicity data, California was awarded a “C” grade for AI/AN data collection overall. The pandemic response showed that current data collection practices were insufficient in meeting the needs of California’s diverse communities.

Beyond race/ethnicity, jurisdictions do not have the capacity, staff, or data to accurately or thoroughly track equity impacts along other dimensions, including place-based factors. Just under one-quarter of local public health departments responding in the LHD Data Survey (24%, n = 17), tracked indirect COVID-19 impacts, such as job losses or housing or food insecurity in their vulnerable communities. When asked what data would be helpful for their COVID-19 response among these communities, LHDs listed a broad array of factors including income, access to care, medical mistrust, employment, housing insecurity, and household size, along with more accurate population denominators. At the level of local public health departments, the will to more inclusively track equity impacts is there, but the data and capacity are not.

JUST UNDER ONE-QUARTER OF LOCAL HEALTH DEPARTMENTS TRACKED INDIRECT COVID-19 IMPACTS



Both the State and local public health departments have taken action to address aspects of the challenges outlined above. While much work remains to be done, it is important that the practices listed here are uplifted; improving data collection practices is critical to supporting communities and identifying health inequities.

At the state level, **California took regulatory action** in July 2020 to mandate the collection of race/ethnicity and sexual orientation and gender identity data. Action at this level has the ability to create wide-reaching impacts, but it must be implemented thoughtfully. While collection of these data is now mandated, it does not prevent data reporters from entering “unknown” or “other” in any required field. Systematic, institutional change is necessary to truly improve data collection across the board.

This can start with outreach to communities. **A report on race/ethnicity disparities in COVID-19 outcomes** spurred the Los Angeles Department of Public Health to create an Asian & Pacific Islander Task Force. One focus of this Task Force is improvement of disaggregated data collection and reporting among the Asian American, Native Hawaiian, and Pacific Islander communities in Southern California.

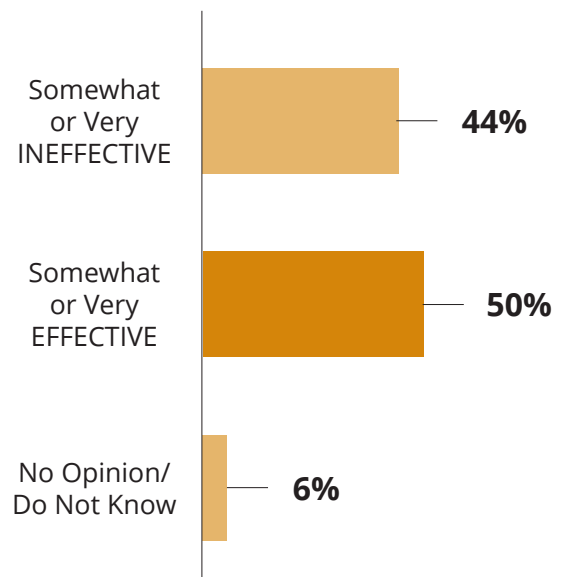
In August 2020, the Urban Indian Health Institute similarly published a detailed set of **best practices for American Indian and Alaska Native data collection**. In addition to a collection mandate, they include linking data sets to correct misclassification, ensuring data collection instruments allow for the selection of multiple races, and disaggregating data wherever possible when reporting.

2. Outdated and inflexible data systems paired with a lack of data standards failed to meet demands of COVID-19 response

When surveyed about the condition of their data systems (in place prior to, and at the beginning of, the COVID-19 pandemic), nearly half (44%) of local public health department leadership rated their data systems as “somewhat” or “very” ineffective. Respondents identified collection of demographic data, hospital data, and case reporting, investigation, and management as the top challenges presented by the existing data infrastructure. Collection of lab data and production/reporting of State-required metrics were identified by respondents as lesser but still impactful issues.

As COVID-19 cases surged, limitations of the existing data infrastructure impeded the response of LHDs, including a reliance on faxed and paper records and insufficient data standards that limited efficient, timely, and complete data exchange between healthcare providers, the State, and local systems.

HOW EFFECTIVE HAVE YOUR EXISTING (IN PLACE PRE-COVID) DATA SYSTEMS/ SURVEILLANCE BEEN IN SUPPORTING COMMUNITIES MOST VULNERABLE TO THE IMPACTS OF COVID-19 THROUGHOUT YOUR RESPONSE?



The California Reportable Disease Information Exchange (CalREDIE) is a tool provided by the State to local public health jurisdictions for electronic disease reporting and surveillance. Launched in early 2010, all California counties, [with the exception of San Diego and Los Angeles](#), use CalREDIE as an integral component of their communicable disease programs. [Per the California Department of Public Health](#), the vision of CalREDIE is to “improve the efficiency of surveillance activities and the early detection of public health events through the collection of more complete and timely surveillance information... It maximizes prevention efforts by allowing public health information from physicians and laboratories to be tracked and analyzed by the Division of Communicable Disease Control (DCDC) and LHDs.”

As shared by our survey respondents, CalREDIE fell short of this vision during the COVID-19 pandemic:

“CalREDIE... make[s] managing high volumes of data near impossible, because steps require so much human input. When comparing to an EHR [electronic health record], things that should be simple are just not developed... A simpler and more systematic workflow is needed to streamline and allow for voluminous data flow.”
LHD respondent

Among several issues identified by the LHD survey respondents, two have significant equity implications and are highlighted here.

The first is limited functionality to add new fields, which would allow LHDs to rapidly collect information on emerging risk groups, populations, occupations, and more. For example, early in the response there was no easy way to identify incarcerated, skilled nursing facility, or other congregate setting cases. Jurisdictions were required to manually track variables of this type. After LHDs shared this concern to the State, CalREDIE was updated to support the addition of user-defined fields to the person under investigation tab to capture these data.

The second concerns the built-in geocoder (a tool used to convert addresses to points on a map). Geocoded case data is an invaluable tool for LHDs to identify geographic “hot spots,” and track the spatial spread of a disease. CalREDIE’s geocoding function, per local public health department experience, has limited functionality. Small LHDs may not have the capacity or expertise required to manually geocode and map case addresses, which could lead to missed clusters of disease, hamper outbreak investigation, and make it difficult to identify the most impacted communities.

Because CalREDIE was “cumbersome and slow” (per one respondent to the LHD Data Survey) when faced with the demands of pandemic reporting, the State stood up an auxiliary system –CalConnect– over summer 2020 to support case investigation and contact tracing. CalConnect interfaces with CalREDIE, and is designed to seamlessly transfer data between the two systems. LHD staff responding to the LHD Data Survey found CalConnect did not meet expectations, at least initially:

- “Case data management is a challenge especially with cases being locked in CalConnect.”
- “We struggle with functionality of CalConnect for us and our staff.”
- “CalConnect is so complex that the data is poor because it is so easy for staff to miss entering info especially in re: exposure events and linking cases to exposure events, and referral for resources.”

The issues with CalREDIE and CalConnect highlight a broader challenge related to State and local public health data systems: they are not setup to communicate with each other or with key healthcare and lab partners. Ideally, providers, labs, and LHDs could share data electronically, seamlessly, and instantaneously between themselves and the State. In practice, it is much different.

State and local public health department data systems were not designed, at the outset, to handle the volume of data generated by, and reporting required in, response to the pandemic. During one LHD interview, staff noted a fundamental mismatch in data systems: as the pandemic ramped up, some partners were still recording data on paper. Based on an interview with a health plan in Southern California, LHDs were not prepared to effectively share data outside of their internal systems, and said it was easier for them to get data directly from testing companies, like LabCorp and Quest. One county echoed this from the perspective of the local public health department during an October CACDC meeting, noting that “providers are to the point where they can export a lot of info from their EHRs, but LHDs have no way to get it into CalREDIE in a timely way.” In this same discussion, it became evident that CalREDIE lacks an automated import or bulk upload function for clinical partners, and many jurisdictions do not have the capacity to support manual data entry. This results in delayed communication between LHDs, the State, healthcare providers, labs, and, ultimately, COVID-19 cases and contacts.

Overall, inefficiencies within five primary data sharing pathways were identified:

1. PROVIDERS (HOSPITALS, LABS, CLINICS) → LHDs VIA PAPER OR FAX REPORTING

This requires manual input by LHD staff – already limited in capacity - into CalConnect or CalREDIE.

2. PROVIDERS → LHDs VIA ELECTRONIC REPORTS

CalREDIE’s Provider Portal and confidential morbidity reports (CMRs) allow providers to directly submit to CalREDIE. While these streamline provider reporting, LHDs have noted that providers frequently submit incomplete reports, requiring staff to follow-up –if they are used at all. According to one respondent to the LHD Data Survey, “many providers are not reporting via CMR and/or CMRs are barely filled in.”

Outside of CMRs and the Provider Portal, electronic spreadsheets are another mode used by outside entities to transmit data to health departments. In early August 2020, CDPH required labs to submit spreadsheets directly to LHDs with COVID-19 test results,. This process change came without enough details for LHDs to efficiently operationalize this reporting shift, as discussed in an August post on the CCLHDME forum. Functionally, electronic spreadsheets and faxed or paper records are much the same to LHDs: they require manual input into CalREDIE.

“The hospital data from hospitals is often messy or doesn’t make sense. it would be great to know the age make-up of each of our COVID hospitalizations for modeling purposes. But, this data is either missing or doesn’t add-up.”
LHD respondent

3. MULTIJURISDICTIONAL HOSPITALS AND HOSPITAL SYSTEMS → LHDS VIA MULTIPLE SYSTEMS

Entities that work across jurisdictional boundaries are required to submit reportable conditions (e.g., COVID-19 outcomes) to all local public health departments in the jurisdictions they serve. With limited coordination, each LHD sets its own preferred format for, and method of receiving, reports. As a result, hospital systems can be required to produce multiple versions of the same report and transmit them in multiple ways, including via fax, secure email, or secure file transfer protocol (SFTP). This places a burden on the reporting hospitals that can result in poor quality data.

4. LHDS → CDPH VIA PAPER REPORTS

Case investigation (CI) and contact tracing (CT), particularly in smaller jurisdictions, is sometimes done on paper. A jurisdiction responding to the LHD Data Survey reported that “CI/CT is easier done over the phone with paper forms, but that makes State required reporting very time consuming when resources are stretched thin.” Paper forms must be input into CalREDIE (or CalConnect, then synced with CalREDIE) by LHD staff, essentially a duplication of work when capacity is already extremely limited.

5. LHDS → CDPH VIA ELECTRONIC REPORTS

Electronic CI/CT reports, taken through CalConnect, must still be input into CalREDIE. This is done via an automated process that synchronizes data between CalConnect and CalREDIE. LHDs raised numerous issues with this synchronization system when it launched:

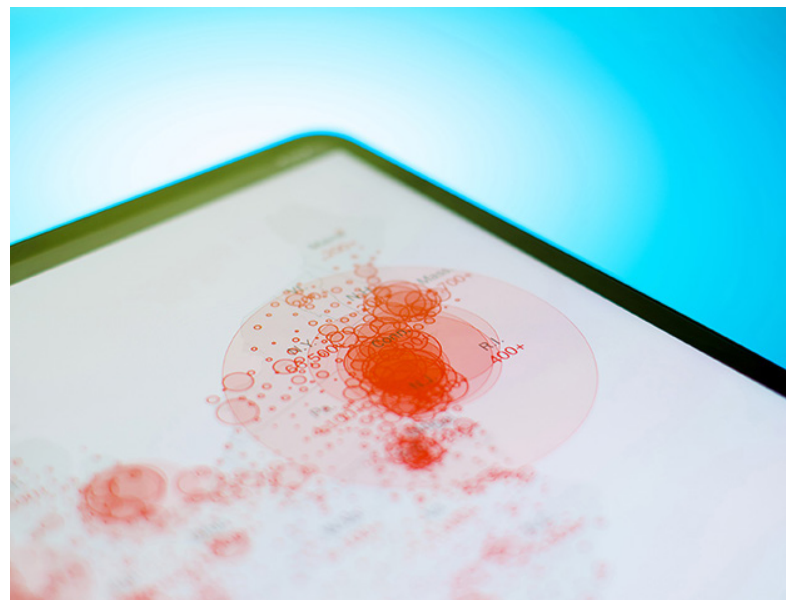
- Not syncing frequently enough for volume of cases (only once or twice per day)
 - » Some jurisdictions resorted to manually entering data in CalConnect and CalREDIE instead of programmatically

pushing it back and forth; meaning staff had to enter case and contact data twice.

- Date of death field was frequently cleared
- CalConnect overwrote CalREDIE data, leading to loss of data

An important factor contributing to many of these inefficiencies is that health systems – in contrast to State and local public health departments - received a decade of Meaningful Use incentive payments to modernize their data systems and promote widespread adoption of electronic health records. Lacking the resources to regularly update and upgrade their own systems, it was inevitable that State and local public health departments would fall behind.

Functional data systems are the cornerstone of an effective public health response. They are integral to rapidly identifying impacted communities and responding to their needs. Delays or barriers to data sharing, as described here, can exacerbate, or even miss, serious inequities in health outcomes. Nevertheless, improvements within the pathways outlined above have come piecemeal over the course of the pandemic response – driven largely by emergency infusions of funds from the federal government - but many challenges remain.



Best Practices

Ideally, data are 1) accurately captured at the point of origin once and, 2) successfully passed through to other data systems via standardized protocols. In this case, patient self-identification (for demographic measures), or clinical diagnoses in primary care settings recorded in practice management systems/electronic medical record and sent via secure electronic protocols (e.g., HL7) to other care providers (laboratories) and public health agencies. As revealed by the pandemic and evidenced above, data collection and sharing fell short of these ideals. However, some successful enhancements were made during the pandemic that should be considered in response to future public health emergencies.

When the existing CI/CT infrastructure and reporting pipeline proved insufficient, the **State stood up the CalConnect system** for LHDs. Despite challenges in implementation, detailed above, for many jurisdictions it standardized and streamlined the CI/CT process.

The State also recognized that CalREDIE overall – as a communicable disease reporting system and database – was outdated and lacked many features expected of a modern tool (e.g., bulk uploads, field customization, interoperability). Engaging a contractor (Deloitte), the State sought extensive input from LHDs on data workflows, needs, and challenges through a series of interviews and focus groups. These were used to inform a “CalREDIE 2.0” landscape analysis, capturing the needs of its primary users.

Further, regularly surveying LHDs and developing tools and resources to support local response, like **CDPH’s LHD Contact Tracing Program Readiness Survey**, can help identify immediate needs and complement long-term planning.

Among local public health departments, the burden of reporting twice —once to the State, and once to the public— was eased markedly by developing public-facing data dashboards that pull directly from internal tracking tools. One respondent in our LHD Data Survey noted that:

“Connecting our public-facing databases to CalREDIE/CalCONNECT fields makes it easy to maintain. The underlying data is still poor, but there is not a lot of maintenance required.” LHD respondent

3. Missing or incomplete methodology provided for State-required COVID-19 surveillance and reopening metrics

A keystone component of any disease surveillance system is clear, consistent case definitions. All reporting parties must agree on what constitutes a “confirmed” or “probable” case or death; without this agreement, they are not counting the same thing. This can have significant repercussions in identifying and responding to disparities in COVID-19 outcomes.

Throughout 2020, local public health departments repeatedly voiced concerns about these core measures on CCLHDME and CCLHO calls, and the impact on their workload. LHDs frequently

reported that case and death totals did not match those reported by the State. As late as December 2020, there was still no universal agreement on assignment of confirmed and probable deaths based on location of COVID-19 on the death certificate; one attendee of the CCLHDME call where this was discussed stated that “death certificates are going to be the indelible dataset... We really need CDPH to stand up and set a standard for how to count these deaths.” Further, no guidance was provided on counting deaths re-allocated from one jurisdiction to another (such as when the decedent is a nursing home resident in county A but their permanent address is in county B). Per a LHD epidemiologist on a CCLHDME call, “I would rather have clear guidelines from the State on this, than to say it is up

to the LHJ.” During another October 2020 CACDC call, a jurisdiction shared that: “We’re looking to CDPH to tell us how we should report, not the other way around.”

Without clear definitions, and precise, reproducible methodology, this created an incredible workload burden for LHDs. Jurisdictions regularly had to troubleshoot mismatched reporting between State and local measures, including “back-engineering” the data. Worse, this troubleshooting often occurred in a vacuum: each LHD had to discover and fix the same problems, independently. One LHD epidemiologist on the CCLHDME message board put it succinctly:

“The reconciliation of local data vs CDPH counts has caused so much extra work for our epi[demiology] staff this summer, additionally the data discrepancies have added to more negative press for our PHD/ Epi team.” LHD respondent

Time spent reconciling different data sets is time LHDs did not have to respond to equity concerns, with real impacts on public perception of State and local public health departments.

An illustrative example, from the fall of 2020, concerns reporting of results from SARS-CoV-2 antigen tests. Antigen tests, compared to the “gold-standard” real-time reverse transcription polymerase chain reaction (RT-PCR, or simply PCR) tests, offer an inexpensive, rapid method of COVID-19 testing. Many workplaces and congregate settings requiring repeated COVID-19 tests find antigen tests an appealing alternative to PCR testing for these reasons. However, antigen tests are “[generally less sensitive](#)” than PCR tests in detecting SARS-CoV-2,

and require careful interpretation to recognize false negative or false positive results. With increasing usage of antigen tests, how the results from these tests are reported (or not) varied dramatically from jurisdiction to jurisdiction, per an October CACDC call:

- One county in Southern California counts them as “confirmed” cases, but separates them out when reporting to the State
- Several others record and report them as “probable” cases
- At least one county is not differentiating between antigen and PCR tests, and reporting all as confirmed
- Many others not yet publicly reporting, but know they will need to start reporting soon

One LHD on the CACDC call noted that they have de-emphasized antigen/probable test reporting because they want to be consistent with what is reported by the State, and that “it would be nice if we had some consistency across counties, and from county to state.” Another shared concerns about an eventual public rollout of antigen test reporting, saying they “don’t want it be a ‘big reveal’ to the public... hope there is a thoughtful rollout... including workload & PH communications.”

Without consistency in reporting, it has been difficult for local public health departments to maintain trust in the public view. This trust is paramount to effectively tracking and responding to health disparities: without cooperation from impacted communities, it can be challenging to affect change.

In late August 2020, the State released its [Blueprint for a Safer Economy \(Blueprint\) framework](#). The Blueprint framework includes a series of COVID-19 metrics that dictated the ability of each county to re-open portions of their economy. Because of its impact on businesses and subsequent high profile, Blueprint metrics were subject to additional public scrutiny, leading to further challenges for local public health departments. Of note: missing or incomplete

methodology limiting the ability to replicate State metrics locally, and insufficient engagement of LHDs in the metric development process.

The former has been an ongoing topic of discussion on CCLHDME and CACDC calls since the launch of the Blueprint. Many LHDs found that they could not reliably reproduce Blueprint metrics. According to reports shared on these calls, requests made by LHDs for the State to release detailed methodology, statistical code, or important source data (such as line lists of cases/incident IDs included in the case rate) frequently went unanswered. One jurisdiction, on a September CACDC call, noted that “we are struggling to respond to our PH officers and county boards” due to discrepancies in State and local calculation of Blueprint metrics. Overall, better inclusion of LHDs in the development of these new metrics could have eased these challenges in the rollout.

Best Practices

The State took a promising step towards data transparency by spooling up a Github site to share, with local public health department epidemiologists, the statistical code used by CDPH to generate Blueprint metrics. This had the potential to provide significant clarity on calculation of the metrics, including details of inclusion and exclusion criteria, and precluded the need to “back engineer” metrics.

In addition, CDPH’s own CDC Epidemiology and Laboratory Capacity for Prevention and Control of Emerging Infectious Diseases (ELC) grant reporting team modeled a collaborative metric development process. CDPH staff on this team actively sought input from local public health departments, at multiple levels, on the development of ELC reporting metrics. LHDs were given several opportunities to weigh in on proposed measures, and could raise concerns or methodological questions before being asked to adopt brand-new metrics.

4. Communicating data to communities

Over the course of the pandemic, the public has seen conflicting data reported by State and local agencies. Inconsistencies in the measures themselves (such as the definition of a COVID-19 case, or the COVID-19 test positivity rate) is an important problem, but may not be as visible to the public. However, inconsistencies in what is and isn’t reported between State and local data dashboards is far more visible, and has led to confusion, mistrust, and frustration.

People are invested in the health of their communities, and often want to be part of the solution to address disparate impacts. Their participation hinges on clear, consistent, and detailed reporting on local public health outcomes, including COVID-19. State and local agencies, attempting to balance privacy and actionability, took different approaches to mixed results.

The State is very conservative in its public reporting, sharing aggregated data at geographies no smaller than county, and only reporting certain measures, such as COVID-19 cases by race/ethnicity, at the State level. This has made it more difficult for the public to be informed about impacts to their specific communities, and limits their ability to engage directly in solutions. It is also counter to recommendations made in the State’s Portrait of Promise: The California Statewide Plan to Promote Health and Mental Health Equity: “Data that allows us to see disparities at the level of social determinants of health, and that is disaggregated in ways that make our often- invisible communities visible, has been hard to obtain but is vitally important.”

The State’s reporting choices are largely informed by the California Health and Human Services Agency’s Data De-Identification Guidelines (DDG). CDPH frequently cites the DDG recommendation to report data only at geographies with populations above 20,000 (excluding census tracts, ZIP codes, and even many cities) as justification for this conservative approach.

As a result, communities who sought to understand COVID-19 impacts not only in their county, but in their city or neighborhood, were unable to get detailed data from the State.

Local health departments have often tried to provide more granular data. Some jurisdictions have chosen to report COVID-19 cases aggregated to the level of census tract. Others are reporting at the ZIP code, city, or unincorporated community/ Census-designated place level. Many jurisdictions also report COVID-19 outcomes by race/ethnicity. By providing data at smaller geographies and stratified by important measures like race/ethnicity, these approaches are generally more welcoming to community participation in addressing disparities in COVID-19 impacts.

In some cases, however, this openness and transparency in reporting led LHDs to experience push back from some community members, who felt it was an intrusion. This has been felt particularly in the CI/CT process, which gathers some sensitive demographic characteristics, including sexual orientation and gender identity (SOGI). An attendee of a September CACDC meeting noted that:

“We are already speaking with county residents who feel that the government is being intrusive. This question [on SOGI] adds to that feeling and has a very negative impact on our interviews.” LHD respondent

Another shared that “in rural conservative areas, this can really alienate people we are already struggling with.” Beyond SOGI, one respondent to the LHD Data Survey wrote that “we see a high rate of non-cooperation with naming contacts, especially with families who have foreign born family members (Hmong and Latinx in our county) but

also among white, COVID-deniers. Somehow we need to establish trust and credibility with these populations.” Based on these responses, some jurisdictions shared that they don’t want to report these data publicly, given concerns about undue bias against certain groups.

State and local agencies must carefully balance data transparency and personal privacy to maintain the public trust and facilitate a collaborative public health response with full participation from communities. Neither the State nor LHDs struck precisely the right mix during the pandemic, and discrepancies in reported data exacerbated this challenge: during an October CACDC call, participants shared that inconsistency between what LHDs versus the State reports has been a significant source of dissatisfaction among the public. There has been general feedback from LHDs that improving our public data reporting will help alleviate these frustrations, and ensuring that all parties – the State and LHDs – are aligned in what they report is key. As highlighted in the State’s Portrait of Promise strategic plan communication goals, it is important that the State and LHDs center public feedback, and community needs, in the development of a unified reporting approach.



Best Practices

The disparate approaches in collecting and publicly reporting COVID-19 data has resulted in many challenges *and* many successes. Local health departments that chose to release data disaggregated by gender and race/ethnicity, as in [Santa Barbara County's COVID-19 Community Data Dashboard](#), enabled the public (including public health researchers and community-based organizations) to monitor disparities in their communities. San Francisco publishes [cumulative case rate maps at the census tract level](#), a spatial resolution fine enough that communities could see the impacts not only in their city, but in their specific neighborhood.

Jurisdictions like Monterey, with their [Disparate Impact Report](#), and Los Angeles, with their [COVID-19 Racial, Ethnic & Socioeconomic Data & Strategies Report](#), took this a step further. By analyzing their data to better understand the COVID-19 among their vulnerable populations, Monterey and Los Angeles were able to identify local strategies and resources to address disparities in COVID-19 outcomes. Making these reports publicly available – instead of siloed within the health department – brings community partners to the table with actionable strategies.

At the state level, California took an important step towards institutionalizing the importance of making key data publicly accessible in a [memo on COVID-19 Data Transparency](#) dated June 25, 2020. The State wrote that “all agencies are required to make data open and machine-readable within 60 days,” so that “researchers, scientists and others can use these data and trends in their ongoing work to combat COVID-19.” While setting an excellent precedent, prioritizing data access for practitioners involved in the COVID-19 response sooner would have been a welcome and important addition.

And, while the CHHS DDG is imperfect, it is part of an impactful suite of open data tools – [the Open Data Handbook and Data Playbook](#) - that facilitate data sharing, including guidelines for publishing data in machine readable formats, in online dashboards, and compiled into easy-to-read reports for the general public, community-based organizations, and elected officials.





RECOMMENDATIONS

The COVID-19 pandemic revealed significant data barriers within local and state public health departments. It also made clear what is required to modernize public health data systems. State and local public health departments now have an unprecedented opportunity to meaningfully address these challenges and build better public health systems that center health equity.

To accomplish this, we must focus on data. Data play a vital role in an effective and equitable system. The recommendations outlined here re-envision existing data systems; prioritize the participation of local public health departments and community stakeholders in data policies and reporting practices; support development of health equity metrics across California; and expand and improve the collection of key demographic data that are the basis for equity work. In all, these would support State and local efforts to identify, track, and address health inequities. And, they would facilitate closer collaborative relationships between government, healthcare, and the public, making equity a cornerstone of future work.

Support development of modern public health data infrastructure

As the backbone of public health work, data systems are a critical component. During the pandemic, shortfalls in existing systems revealed significant opportunities for improvement. Post-pandemic, the State could play a transformative role in upgrading and modernizing the public health data systems that local public health departments rely on for their vital work.

A new public health data infrastructure, brought fully into the 21st century, would include:

1. standards for data interoperability,
2. clearly defined data sharing protocols,
3. regularly updated, core datasets,
4. uniform data collection and input practices,
5. and a commitment to transparency in public reporting, with features and functions designed to support this.

In addition, a fundamental component of modern disease surveillance systems – “CalREDIE 2.0” – is streamlined integration with provider reporting, case investigation, and contact tracing tools. This “interoperable-by-design” approach ensures that best-fit tools for State and LHDs can work seamlessly with each other.

All components of a modern public health data infrastructure would prioritize flexibility and interoperability. These are the characteristics that facilitate data sharing between and within local public health departments and the State. As not all health departments will use the same suite of software or data tools, it is critical to ensure that all components of a new data infrastructure can communicate is key.

As a first, interim step, existing data management systems could be upgraded or redesigned to support these new infrastructure standards, prioritizing fixes and tools that allow for interoperability. This allows the State and LHDs to select, develop, and use the tools that best suit their needs. As new systems come online, data could be seamlessly transferred between the old and new tools, easing the transition. To prevent data siloing, new systems, either off the shelf or custom developed, must be interoperable by design. With all parties using interoperable systems, data can be shared more quickly, effectively, and completely, enabling a more rapid public health response.

Integrate local public health department stakeholders in state governance of data for policies, practices, and metrics

Public health is fundamentally a collaborative, collective endeavor. In a state as large as California, the most effective public health policies and practices are created with insights provided by those working in local communities across the State, who have on-the-ground expertise.

Formally integrating these local insights into CDPH data practices and decision-making could begin with the formation of a taskforce, comprising representatives of local public health departments alongside select CDPH staff. The taskforce could be charged with envisioning what this close integration might look like once implemented: identifying key stakeholders, gathering input, and drafting guidelines for a collaborative partnership. With support from both the State and locals, these guidelines can be

instituted across CDPH and incorporated into workflows. The existing forum of CCLHDME has some of these characteristics, but in over one year of meetings, LHD participants have noted that CDPH representatives frequently brought near-finished products for comment. The goal of the taskforce outlined here is to equalize the dynamic between LHDs and CDPH in the development cycle, co-creating and seeking LHD feedback earlier in the process.

Through this recommendation, local expertise is prioritized as a core component of CDPH governance, and is aligned with goals outlined in the State's Portrait of Promise strategic plan. It represents a shift from a top-down approach, inviting local public health department data managers and epidemiologists to meaningfully co-create the data policies, practices, and metrics that guide their work.

Institute "health equity metrics" across State and local government operations and investments

The Blueprint Health Equity Metric and Vaccine Equity Metric represent a vital step forward in explicitly considering health equity in decision-making and resource allocation. In the case of the Health Equity Metric, by tying re-opening to improving local public health disparities, it proved an attractive "carrot" to act on issues of health equity. By redirecting resources to the most affected communities, it provides for real impact.

The State has set a transformational precedent. We see the success of the Health Equity Metric as an important milestone in our collective health equity work, and as a foundational model for replication. We envision Health Equity-like metrics as a critical component in a multi-pronged strategy, at the State and local level, for truly addressing equity.

Building off of this initial success could support the development of Health Equity like-metrics across CDPH, other State agencies, LHDs, and local government. Tools like the Healthy Places Index®,

at the heart of the Blueprint Health Equity Metric, are applicable to any agency, State and local, that influences community and social conditions, from transportation and infrastructure to education, housing, and planning.

Health Equity Metrics across the State would institutionalize the importance of considering health, and addressing health disparities, in all facets of state and local work.

Expand and improve collection of demographic data

Accurate data are indispensable to addressing health disparities. By ensuring we collect accurate data, and expanding the categories of data we do collect (such as the social determinants of health), we can better quantify disparate health impacts, and identify new avenues to address them.

However, a significant limitation to action is that public health data systems are populated with data that originates outside the public health system (from clinicians, labs, hospitals, SNF, prison healthcare, and others). LHDs have noted this as a key challenge. One LHD Data Survey respondent said that their pandemic response was hampered by a “lack of will to ensure accurate data are recorded initially [i.e., at the point of care],” and in a CCLHDME meeting a participant called out that “as long as healthcare can report ‘unknown race/unknown ethnicity’ we won’t get good data.”

The most impactful step the State can take to enact this recommendation is to take regulatory action requiring health care providers (clinicians, labs, hospitals, and others) to report demographic data. The regulatory burden on providers has to be weighed against the lives that would have been saved if this information was readily available at the start of the pandemic.

The State’s Portrait of Promise strategic plan notes that “failing to account for a community in data means missing the opportunity to understand and

address that community’s unique challenges, needs, and assets.” Disaggregating data is one of the best approaches to identifying health disparities, and ensures that community members see themselves reflected in publicly reported data. To support this, it is critical that CDPH and local public health departments disaggregate data to the fullest extent possible for both internal analysis and public dissemination. The health care industry has already moved down this path; the National Committee for Quality Assurance (NCQA) Healthcare Effectiveness Data and Information Set (HEDIS) will require health plans to stratify selected outcomes by race/ethnicity by initially using area-based measures and ultimately, individual-level data.

An example of effective data disaggregation is to always separate Asian and Native Hawaiian/Pacific Islander when reporting, because important differences in health outcomes may be missed if they are combined. The Portrait of Promise speaks to this specifically: “while data showing the difference between aggregated populations can be useful, important disparities in health risks may be missed when looking only at this aggregated data for populations designated by large geographic areas of origin, such as Latinos and Asian/Pacific Islanders.” Similarly, report meaningful subgroups of these categories when numbers are large enough. Also consider other data de-identification options, such as limiting stratification by other measures, to protect privacy for small populations.

Building relationships with the community is a core communication goal in the State’s Portrait of Promise strategic plan, and can be invaluable towards discovering population-specific data gaps and identifying solutions. This is especially pertinent for small groups, particularly those in the American Indian/Alaska Native, Asian, and Native Hawaiian/Pacific Islander communities. This can be achieved by partnering with representatives from these communities to collaboratively identify better modes of data collection and reporting.

Standardize data practices statewide, in collaboration with local public health departments, to more effectively track disparities

In concert with expanding data collection as outlined in the previous recommendation, improvements to data practices across the State are key to effectively addressing disparities. This begins by not only collecting demographic characteristics, but doing so in a standardized way. To minimize issues of misclassification, it is important that there are clear definitions for each characteristic. Misclassification can hide the true impact of a health outcome on a population, so this is especially important for race/ethnicity groups such as Native Hawaiian/Pacific Islander, and Other, which are commonly misclassified.

Circumstances that lead to poor quality data collection may never be completely prevented, however. Across many CCLHDME and CCLHO meetings LHDs have requested increased sharing of data processes from CDPH, specifically codebases, that streamline data collection, cleaning, and analysis, making it much faster to identify disparities as they arise and freeing up staff to focus on core public health activities.

Finally, California is a diverse state. As described in the State's Portrait of Promise strategic plan, "we want everyone to be included in these [equity work] efforts, so special attention will be paid to reaching the corners of the state and the individuals and communities that have historically been challenged to participate in statewide dialogue and action."

To meet this goal, approaches for tracking health disparities (such as health equity metrics) can be developed in careful collaboration with local public health departments (when developed by the State) and with community-based organizations (when developed by LHDs). This helps avoid missteps in a "one-size-fits-all" approach. To that end, and in response to LHD requests made on CCLHDME and CCLHO calls, source data and methodology

must be made readily available for review by stakeholders, and published publicly once approved. A commitment to transparency, and community co-creation, can help bolster public trust of State and local agencies.

Support comprehensive and transparent public reporting of impact data

To better meet the communication goals included in the State's Portrait of Promise, and representing an opportunity to prioritize public engagement in State-produced data, is the revision of the CHHS Data De-Identification Guidelines; specifically, to support the public release of disease surveillance data at actionable, community-level geographies, preferably at the census tract level, as recommended by supporters of [Assembly Bill 1358](#) (2021), which include the California Pan Ethnic Health Network, PolicyLink, Latino Coalition for a Healthy California, and the California Black Health Network, among many others.

To further bolster engagement, it would be beneficial to focus on community capacity building to participate in data interpretation and dissemination at the local level. Across several CACDC and CCLHDME discussions, LHDs described challenges resulting from the community misunderstanding of publicly-reported data: COVID-19 testing reticence, refusal to share demographic characteristics with case investigators, and confusion on measures included in the Blueprint. In addition, a commitment to regularly incorporating public feedback in the display and communication of published data could avert some of the difficulties LHDs faced. This would ensure that cultural and community sensitivities are honored, and prioritize a collaborative, bottom-up approach to public health.

Data reported at tract and ZIP code levels can come in many forms, with the goal of providing accessibility to the widest audience. This includes publishing data in machine readable formats, online dashboards, and compiled into easy-to-read

reports for the general public. Reflecting challenges shared by LHDs with mismatched or lagged data compared to the State, data should be updated as frequently and transparently as possible, particularly in public health emergencies. As requested by LHDs, automated processes for data updates and publication can be shared to streamline their own local data updates.

To minimize discordance between State and local reports, and limit public confusion (per one LHD on an October CACDC call, “we know we’ll get a lot of questions when our counts don’t match the State”), the State and local public health departments should endeavor to align their data reporting, incorporating feedback from community stakeholders where possible. This can involve sharing reports, publications, and dashboards with stakeholders before releasing to the public, and providing clear methodology, including data sources, for the calculation of metrics.

Develop a unified, bidirectional statewide health information exchange (HIE) with interoperability between state and local public health departments, and healthcare and hospital systems

Public health practice – at the State and local levels – requires reporting from healthcare and hospital systems. Based on conversations with several California health plans and providers, and from discussions with LHDs held on CCLHDME calls, this has largely been a unidirectional relationship, often with ad-hoc data sharing protocols in place. From these conversations:

- LA Care shared that they participate in three different HIEs
- Community Clinic Association of Los Angeles County (CCALAC) noted that there weren’t enough hospitals participating in the HIEs for them to be efficient or effective

- California Primary Care Association (CPCA) argued that we need a central HIE, and that we don’t need multiple systems like those currently in place for immunization registries

It is a challenge for both parties: hospitals and healthcare systems face an administrative burden in reporting outside of their existing electronic health records systems, and public health departments may get delayed and/or incomplete data. These data are crucial to support direction and refinement of public health programs and resources.

Blue Shield of California summed it up succinctly: the pandemic has supplied “our ACA moment” to rethink our data systems and develop a unified HIE with a mandate for its use. The State can support this new system that is bi-directional, interoperable, and sustainable, to build better data relationships and continuum of care between local public health departments, hospitals, and healthcare systems. The National Academy of Medicine, in its [Health Data Sharing to Support Better Outcomes report](#), details what this might look like, and recommends setting policies that “establish ground rules and standards across networks, as well as support the development of technologies and systems that promote, rather than impede, data sharing.”

In short, development of data standards, core datasets, support for Meaningful Use, and data sharing protocols that allow for streamlined reporting between systems are core components of a unified HIE. These protocols need to build in clear guidance and development of electronic messaging standards, specifically for laboratories and other reporting entities in healthcare and hospital systems to ensure timely, accurate data collection and interoperability with existing State and LHD data systems.