Can Existing Health Information Exchanges Be Leveraged To Modernize Public Health Surveillance?

A Look at California's Efforts To Advance Public Health Surveillance with HIE Data

Surveillance and epidemiology are critical public health functions that prevent and control disease in communities through the systematic collection, analysis, and dissemination of data to inform effective and timely public health actions. They rely on laboratories, providers, and hospitals to report key clinical data on individuals that can identify disease patterns, not just during outbreaks and pandemics, but also to monitor ongoing community health and inform public health practice and policy.

However, manual reporting methods, outdated and underfunded public health data systems, multiple non-interoperable disease reporting systems, and hesitation from some hospitals to share relevant data, even during outbreaks, are major limiting factors to ensuring public health systems have the data needed for accurate, timely surveillance and public health action. This was especially evident during the earliest phase of the COVID-19 pandemic, when some hospitals across the country had to send COVID-19 lab results by fax because there weren't any electronic data feeds to public health departments, and some basic tools like immunization information systems struggled to handle the volume of COVID-19 vaccinations.

In addition, the lack of completeness and/or accuracy of race and ethnicity data in public health systems may conceal pervasive racial and socioeconomic inequities in healthcare access, quality, and outcomes. In 2015, the American Journal of Public Health published a report on missed opportunities in Meaningful Use (specific objectives set by the Centers for Medicare and Medicaid Services that eligible professionals and hospitals must achieve to participate in the EHR Incentive Programs) to address health equity: "The science of eliminating health disparities is complex and dependent on demographic data. The [HITECH Act] encourages the adoption of electronic health records and requires basic demographic data collection; however, current data generated are insufficient to address known health disparities in vulnerable populations, including individuals from diverse racial and ethnic backgrounds, with disabilities, and with diverse sexual identities."[1] We saw this acutely during the COVID-19 pandemic, when Black, Hispanic, and some Asian populations had

[1] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4455508/

substantially higher rates of infection, hospitalization, and death compared with their white counterparts.[2]

Coming out of the COVID-19 pandemic, public health agencies are taking stock and examining their health data systems to prepare for not only the inevitable next pandemic but also to improve their public health surveillance priorities. At the federal level, the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP) and Centers for Disease Control and Prevention (CDC) are closely coordinating on the CDC Data Modernization Initiative and other cross-agency programs to help strengthen the systems, tools, and practices on which health agencies rely.[3] Key objectives include providing public health professionals access to richer and more timely data in ways that put less burden on both data providers and public health agencies, and establishing modern, scalable, cloud-based capabilities.[4]

California is one state leading efforts to explore how to modernize its public health data systems in parallel with ASTP and CDC's initiatives. California Department of Public Health (CDPH) officials have identified a need for more timely health data and recognize building scalable, statewide health information exchange (HIE) infrastructure takes time and resources, especially in the country's most diverse and populous state. Could existing HIE technology from nonprofit health information organizations (HIOs) be leveraged to move toward the goal of effective, efficient, and interoperable surveillance systems — systems that could also ensure more equitable public health?

HIOs already partner in local and state public health

agencies across the country for various use cases, including in California. According to early results in a 2023 survey of 76 HIOs across the country conducted by University of California San Francisco's Department of Medicine in partnership with Civitas Networks for Health,[5] 65 HIOs that collectively operate in 45 states plus the District of Columbia provide data to one or more public health agencies (PHA). Of these 65 HIOs, 65% report data to immunization registries, 63% provide lab reporting, and 59% provide syndromic surveillance reporting.[6]

HIOs also combine and deliver crucial and current health information, such as demographics, encounters, labs, and test results, that can be used to identify and address health disparities, support population health management initiatives, improve efficiency and patient outcomes, and enable patient-centric care that coordinates health, behavioral health, and social services.

In 2023, the CDPH Division of Communicable Disease Control, through funding from a CDC Health Equity grant, set out to explore if HIOs could improve public health surveillance data, and, as a result, health equity. There is often a lag in the reporting and availability of this data, which impacts the ability to rapidly track the spread of disease. Currently, while laboratories report data through electronic lab reporting (eLR), healthcare providers report data to the local health department, and then case managers and surveillance analysts collect additional data directly from patients and/or their providers, which requires multiple communications during and after a patient is under care. Local health departments then report this data to CDPH. The current system may provide rich and longitudinal data but can be resource intensive.

[2] https://www.chcf.org/wp-content/uploads/2021/10/DisparitiesAlmanacRaceEthnicity2021.pdf
[3] https://www.healthit.gov/buzz-blog/interoperability/onc-and-cdc-working-together-to-strengthen-public-health-systems-tools-and-practices-that-keep-us-safe
[4] https://www.healthit.gov/buzz-blog/interoperability/onc-and-cdc-working-together-to-strengthen-public-health-systems-tools-and-practices-that-keep-us-safe
[5] https://www.civitasforhealth.org/wp-content/uploads/2023/11/National-HIO-Survey-Results-Civitas-Networks-for-Health-Presentation.pdf
[6] https://www.civitasforhealth.org/wp-content/uploads/2023/11/National-HIO-Survey-Results-Civitas-Networks-for-Health-Presentation.pdf

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HIOs, however, are purpose-built to exchange health data in real, or near real, time by normalizing, matching, and aggregating data across a network of data contributors — from disease registries to health plans, hospitals, providers, laboratories, and more — resulting in records rich in longitudinal data from multiple sources.

For this pilot, CDPH partnered with two nonprofit California HIOs — a regional community HIO and a statewide HIO, Manifest MedEx — and focused on a retrospective analysis of HIE data.

The CDPH HIE pilot had several goals:

1. Improve public health's reportable disease case data in California to support better understanding of health equity related to access to care, healthcare utilization, quality of care, and health outcomes

2. Evaluate data quality, usability, and sustainability of HIE data for public health workflows and provide recommendations for both the HIE and CDPH for future improvement in informatics and data exchange to support public health priorities

3. Explore the programmatic, regulatory, legal and informatics policy, and technology needed to support ongoing collaboration between HIEs and health departments

The pilot began in January 2023, data exchange was completed in August 2023, and CDPH continues to evaluate data quality, usability, and sustainability of HIE data for public health workflows. In this paper, we take a look at initial findings of the pilot from the perspective of Manifest MedEx. CDPH colleagues plan to submit at least two additional manuscripts for publication that describe in detail the methods and findings of the retrospective analyses of Manifest MedEx-matched data from the COVID-19 and latent tuberculosis (TB) infection registries.

CDPH HIE Pilot: Background and Scope

As California's largest and only statewide nonprofit health information organization, Manifest MedEx exchanges data for 38 million individuals across a network of more than 2,600 providers, 140 hospitals, and 18 health plans in the state. Launched in 2017 as a result of a merger between Emeryville-based California Integrated Data Exchange (Cal INDEX) and Riverside-based Inland Empire Health Information Exchange (IEHIE), Manifest MedEx serves as a critical part of California's health data infrastructure, partnering with the state on various health data initiatives, including processing electronic lab results and case reporting for CDPH and piloting a California Advancing and Innovating Medi-Cal (CalAIM) consent form and management for the California Department of Health Care Services, which administers and provides oversight of California's Medi-Cal (Medicaid) programs.[7,8] The HIO was also designated a California Health and Human Services Agency (CalHHS) Data Exchange Framework (DxF) qualified health information organization (QHIO) in October 2023 and serves as an intermediary to help organizations exchange data across the state as required by law passed in 2021.[9] More than 87% of the California health records Manifest MedEx shares includes patient-reported race data collected from encounters in the past two years.

CDPH and Manifest MedEx collaborated to design the pilot and worked together to identify roles and responsibilities; determine scope; define data exchange standards, privacy, security, and IT requirements; and identify the process for the data exchange and evaluation.

[7] https://www.manifestmedex.org/manifest-medex-successfully-implements-new-data-system-for-the-california-department-of-public-healths-surveillance-and-public-health-information--reporting-and-exchange-saphire/

[8] https://www.manifestmedex.org/manifest-medex-selected-to-participate-in-dhcs-authorization-to-share-confidential-medi-cal-information-ascmi-pilot/

[9] https://dxf.chhs.ca.gov/2023/10/california-announces-designation-of-nine-qualified-health-information-organizations-to-support-secure-statewide-data-exchange-ahead-of-january-2024-deadline/

CDPH HIE Pilot Project: Roles, Process, and Data Exchange

Before any health data could be exchanged, Manifest MedEx and CDPH first worked to reconcile across different data security, privacy requirements, and protection standards in their respective organizations. Both partners worked independently and together to review and implement data user agreements to fulfill their obligations and responsibilities, ultimately determining together that federal regulations, particularly those outlined under the Health Insurance Portability and Accountability Act (HIPAA), were not a barrier to the partnership and sharing of information, but rather provided guideposts for health data exchange outside of the patient care setting for public health surveillance and action. Under HIPAA, an HIO may provide functions and services to its participants (e.g., covered entities, business associates), such as public health reporting to a PHA, patient record location, and data aggregation and analysis.[10]

Manifest MedEx then worked closely with CDPH epidemiologists and CDPH Legal, Privacy, IT, and Security departments to develop a detailed data exchange protocol, including patient matching methodologies, data elements, and security safeguards.

While the nature of data exchange in a health information network typically is characterized as facilitating ongoing, bi-directional data sharing, for this pilot Manifest MedEx agreed to deliver a one-time data file based on two rosters provided by CDPH from its communicable disease data system to enrich CDPH's case reporting datasets:

- Approximately 250,000 patients reported with TB disease (2016-2022) or latent TB infection (LTBI) (2019-2022) statewide

- A statewide random sample of 1 million patients with COVID-19 (diagnosed 2020-2022)

Manifest MedEx matched longitudinal patient records against a number of data match points like first and last names, addresses, and phone numbers, and then returned and uploaded patient health information from its vast network (i.e., demographic data, clinical condition data, utilization data) into a portal in the cloud to facilitate secure transfer of the matched dataset to CDPH.

The two patient rosters resulted in match rates from 40% to nearly 60% with the Manifest MedEx network after duplicates were removed:

- TB/LTBI patient roster: 41% of TB patients were matched and found in the Manifest MedEx system, and of those 41%, 93% had 1+ clinical records since 2022.

- COVID-19 patient roster: 58% of COVID patients were matched, and, of those 58%, 92% had 1+ clinical records since 2022.

Under HIPAA, patients are allowed the opportunity to opt out of their data being included in the Manifest MedEx HIE. For the TB roster, approximately 10% of the original roster from CDPH had opted not to participate in data sharing through Manifest MedEx, and, as such, their information was not provided to CDPH. For the COVID-19 patient roster, 7% of the patient roster opted not to participate in data sharing through Manifest MedEx.

[10] http://www.hhs.gov/sites/default/files/hie-faqs.pdf

CDPH HIE Pilot Project: Preliminary Findings

While CDPH continues to evaluate the value of the enriched data received from Manifest MedEx, here are some preliminary findings from the pilot:

- **Race, Ethnicity and Language (REaL) data for more than 50% of TB/LTBI and COVID-19 patient roster before opt-outs were removed.** Specifically, Manifest MedEx had REaL data for these records as follows:

REaL Data	TB/LTBI Patient Roster	COVID-19 Positive Patients
Race	79%	71%
Ethnicity	59%	52%
Language	67%	58%

For its matched dataset of COVID-19 cases, and LTBI cases, CDPH identified increases in completeness of: race/ethnicity data fields from 74% to 87%, and 45% to 94%, respectively; and language data fields from 28% to 67% and 0% to 65%, respectively, with the REaL data from Manifest MedEx.

- **Patient data from more than one source.** Overall, 90% of the patient records provided back to CDPH from Manifest MedEx included data that originated from more than one data source (e.g., ambulatory providers, clinics, hospitals, health plans), indicating richness in data.

- **Effective referential patient matching systems.** Manifest MedEx's referential patient matching system employs multiple data points to determine a patient match, including phone number. During the exchange process, the system identified a significant number of CDPH COVID-19 patient records with obvious fictitious self-reported phone numbers, possibly due to sensitivities and stigma

around a positive COVID-19 result. Despite the inaccurate phone numbers, Manifest MedEx was able to match 40% to 60% of these records through other data points.

Given the encouraging match percentage and delivery of clinical data, these preliminary findings suggest HIE data can provide data aggregated from multiple clinical sources to better advance public health surveillance.

Additionally, the outcomes suggest many possible public health use cases for HIE data to advance health equity. The pilot identified a few possibilities based on a survey of the data:

- Empowered with more REaL data, public health departments will be more equipped to launch targeted culturally and linguistically responsive public health campaigns in specific zip codes experiencing health disparities. In the data provided by Manifest MedEx, 67% of TB and LTBI patient records contained information about their primary language. Having these simple but critical data points at an individual level informs public health and provider partners about the need to potentially include additional language- and culture-appropriate care in specific communities. Subsetting the data by other demographics, such as age and sex at birth, may allow detection of other nuances in health outcomes and develop tailored quality improvement and public health campaigns.

- By increasing and analyzing both REaL and clinical data, public health departments gain insight into variables like patient outcome and utilization for different cultural and linguistic groups. For example, a preliminary look into the COVID-19 patient records provided by Manifest MedEx revealed that 48% of African American/Black patients had no outpatient encounters on record, but 53% did have one or more emergency room visits, which may indicate potential access to care barriers.

- Public health departments may be able to leverage HIE data to identify disproportionate amounts of chronic conditions that may increase the risk of poor

outcomes for individuals with infectious disease. For example, we identified high frequencies of chronic kidney disease (CKD) in the Black population and high frequencies of obesity in the Hispanic population. Further epidemiologic analyses would be required to determine if our preliminary findings actually represent specific health disparities between different racial, ethnic, language, and rural/urban groups. Additional analyses could focus on health outcomes and utilization of services such as the emergency department, by examining longitudinal health records found in HIE systems.

Conclusion: A Healthier, Equitable Future, Driven by Health Data Exchange

As California continues to expand data exchange, additional data, such as Sexual Orientation and Gender Identity (SOGI) and social drivers of health (SDoH), will become more available through HIOs. The exchange of these standardized SDoH and SOGI data elements continues to increase through the CalHHS DxF, SDoH documentation requirements under CalAIM, and as the Centers for Medicare & Medicaid Services (CMS) prioritizes new Z codes for reporting certain SDoH domains. Coupled with quality clinical data, these data elements are critical to enable public health surveillance functions, advance a more holistic approach to care, such as by identifying housing insecurity and those already unhoused, and advance efforts to address health disparities.

Modernizing our approach to public health means providing state and local health departments access to richer data in real time, driving informed decision making, and allowing public health departments to act with both speed and precision. Now is the time to work toward a new public health future and to build upon existing HIE infrastructure. Armed with data-driven insights, state and local public health systems have an opportunity to impactfully improve health equity and invest limited resources where they will save the most lives.

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