PAPER II

USING HEALTH INFORMATION EXCHANGE TO SUPPORT PUBLIC HEALTH AGENCIES

CIVITAS
Networks for Health
Abstract
We interviewed informants in 52 states and territories on the means they use to promote interoperability of health records and how the resultant Health Information Exchange (HIE) infrastructures are used to support state and local public health agencies. In this paper, we categorize the offerings from HIEs to public health agencies, reporting on the prevalence of the services.

Background
Most state\(^1\) governments have actively promoted HIE within their jurisdiction.\(^2\) Even in states that have taken a hands-off approach to HIE development, private actors have usually built one or more HIEs that operate for the state or a subregion. State government, and especially departments of health, are often receiving services from these organizations. In total we identified 43 states or territories in which public health agencies are relying on a local HIE organization for at least one capability. Many states designate one or more nonprofit HIEs (29 states) or build capabilities within a department of state government (nine states) to serve the state in a particular role, tackling health data interoperability challenges that may not be otherwise solved.

When an HIE is designated by the state, it typically agrees to abide by rules and restrictions designed to protect patient privacy and to give state agencies confidence they can safely rely on within the organization to handle sensitive data. These restrictions may be enforced through legislation, via regulation, contractually in a designation agreement, or by some combination of these mechanisms. In about half of the states with private HIEs, government agencies can procure services from a designated HIE more easily than from another commercial company, e.g., with easier sole source justification. The arrangement can make the HIE a convenient way for departments of health (DOHs) to get work done. Speed of execution and subject matter expertise are attributes these HIEs seek to offer DOHs.

Public health agencies leverage their state HIEs in a variety of ways, with many unique examples cited during our interviews. Both DOHs and HIEs tend to openly share and learn from each other,\(^3\) so approaches that are successful in one jurisdiction are often picked up by peer states. In this paper we categorize the services HIEs provide to public health agencies, describing examples from our research. States with HIEs that provide robust services to public health agencies can generally be considered to have a Health Data Utility.\(^4,5\)

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\(^1\) For readability, we use the generic “states” to include Puerto Rico and the District of Columbia in this paper.

\(^2\) See our companion paper, “A conceptual model for how states engage HIEs.” April 2022.

\(^3\) The researchers note here that during our interviews very few state participants were hesitant to describe all the work underway in their organization.


Categories of Support
We found that most support for public health agencies can be grouped into one of four categories.

### Reporting to Public Health Agencies
Easing the burden of mandatory reporting of health events and other data submission

### Use by Public Health Employees
Collecting clinical records from healthcare providers as part of investigation or treatment

### Enhancing Data
Combining data sets, via patient linking, to enhance data or improve accuracy

### Pushing Public Health Data to the Field
Using records collected by health agencies to assist clinicians at the point of care

**Reporting to Public Health Agencies**
Public health agencies have longstanding authority to require clinicians and health care organizations to report data, both patient identified, as for example each instance of an infectious disease diagnosis, and in the aggregate, such as for bed capacity and ED volumes. Many HIEs serve as a vehicle to report such data to public health agencies — either as the sole mechanism or as one option among multiple reporting mechanisms. HIEs often specialize in developing technical interfaces to enable interoperability and improve workflows. By combining multiple reporting requirements through a single connection, states can reduce the reporting burden on the delivery system

- Forty states indicated that their HIEs support organizations reporting to public health agencies.
- Electronic labs interfaces were commonly cited by our interviewees as reportable data supported by HIEs.
- Some HIEs operate or enhance syndromic surveillance capabilities for a public health agency.

Many states leveraged their partnership with an HIE to facilitate reporting on COVID-19 statistics, especially at the start of the pandemic when information needs were pressing. For instance, state health commissioners were eager to understand the number of ventilators and stocks of PPE available at each acute care hospital. HIEs that had existing connectivity and
credentialed users within clinical organizations were a convenient means to quickly implement these new reporting requirements. For example, West Virginia’s Department of Health and Human Resources relied on its state-designated HIE to enable skilled nursing facilities to report the results of COVID rapid tests.

HIEs are sometimes able to serve as a proxy for mandatory reporting, providing insights without increasing the measurement burden on the delivery system. For instance, during the pandemic, real-time hospital admission/discharge/transfer messages (ADTs) served as a proxy for ED patient volumes, the reporting of which was likely already happening but not in real time. HIEs already had that data aggregated, and daily reports could be created with little additional effort, as for example by Colorado’s CORHIO. Such proxy reporting may lack the precision of a mandated process, which is more likely to have well considered exclusion criteria and to be reviewed by a health system employee for accuracy prior to submission. However, the methods are often accurate enough for their purposes and can be implemented quickly and at a low marginal cost.

**Use by Public Health Employees**

In 38 states, public health employees are using patient identifiable data within an HIE as part of their work, with a common purpose being to support case investigations. For instance, public health workers in Vermont uses the VITL HIE to investigate cases of infectious disease. This use of the HIE was initially enabled for investigation of COVID cases and was later expanded through the Vermont Department of Health’s Reportable Communicable Disease Rule to include all reportable diseases. Another common use is for HIEs to send notifications to care managers inside the public health agency. For example, in Maryland if a person who was receiving antiretroviral therapy for HIV has been “lost to care,” care managers in the DOH are notified by the state designated HIE when the individual shows up at a hospital emergency department. DOH care managers can, through follow-up, help an individual resume important treatment. Standards differ among states as to when public health regulations allow access to clinical data or when treatment relationships exist, but in most cases an HIE can facilitate processes that are allowed but otherwise cumbersome.

**Enhancing Data**

A role for which HIEs may be uniquely qualified is to enhance the data collected by public health agencies by combining them with other clinical records (23 states report using their HIE this way). This activity seems to have increased significantly during the COVID pandemic when a common use was to improve the demographics associated with COVID case files (e.g., New York and its regional HIEs). These case files often suffer from missing fields, including poor capture of race and ethnicity. By matching patient identities to prior medical encounters and enrollment data, HIEs can fill in the blanks. A legacy of the HITECH Act is that the clinical data public health epidemiologists need for analysis during an epidemic are nearly always being collected electronically and held by someone. The challenge is aggregating the various sources.

Consider an epidemiologist who needs data for an analysis of COVID-19 vaccine efficacy. The core information required to calculate breakthrough infection rates can be obtained by combining a COVID case file with an immunization registry. An HIE’s master person index (MPI) can enable this analysis. To enhance the analysis, our epidemiologist is likely interested in
hospitalizations as an outcome. The ADT messages held by an HIE are a possible source, and length of hospital stay can also be calculated from ADTs. Vital statistics data, held by a state agency, can be linked with these first three sources using an MPI to capture mortality as another outcome of interest. An HIE may hold chronic conditions flags, derived from claims data, such that our epidemiologist can evaluate comorbidities, again by combining existing data. The enhanced dataset will be significantly more useful after being combined with other data sources, and if these already existed in an HIE, no additional reporting burden has been placed on the delivery system.

Health care leaders are paying increased attention to health disparities, and in the above example our epidemiologist may want to understand the disparate impact of COVID breakthrough infections. In our research, we found that many HIEs are aspiring to collect and combine more social factors data with clinical records to make such analyses possible. Many examples exist of HIEs supporting improved analysis by race and ethnicity, but other innovative uses of social factors data are in the planning stage. In Maine, the Department of Health and Human Services (DHHS) has launched an effort with the state HIE (HealthInfoNet) to enhance data, with the aim of having more comprehensive information on health disparities. This work will leverage the HIE’s MPI to link identities in DHHS datasets with clinical records at HealthInfoNet to initially produce an enhanced record with more complete Social Determinants of Health (SDOH) and Sexual Orientation and Gender Identity (SOGI) data.

Among capabilities that are “in production,” we found instances of states using HIEs to combine census block social factors data with public health datasets (e.g., Maryland), and in some states HIEs are capturing screening and intervention data from social services programs, which is enhancing public health datasets and enabling subsequent referrals (e.g., QHN in Colorado). HIEs in California\(^6\) and Nebraska have analyzed gaps in preventive care for children, which were exacerbated during the pandemic, highlighting the correlation of certain social factors with these gaps. Public health leaders can use these near real-time analyses to target their efforts to reduce disparities.

**Pushing Public Health Data to the Field**

Historically, patient identifiable data submitted to public health agencies has been used for case investigations, situational awareness, and contact tracing. Such data can also be made available to clinicians in the field, as for example with bi-directional interfaces between a state’s immunization registry and the electronic health records (EHRs) of community providers. In this example, public health leaders want to help clinicians understand their patient’s immunization history by leveraging information received through mandatory reporting. In our study, 36 states reported using an HIE as a conduit to communicate data collected under public health authority back to clinicians in the field. Again, the COVID pandemic seems to have been a catalyst for this use case. Many HIEs partnered with public health agencies to notify a patient’s known primary care provider (PCP) about a positive COVID test (e.g., Delaware’s DHIN) and/or a patient’s immunization status (e.g., New York’s HIEs). Another common use case is to facilitate

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\(^6\) Manifest MedEx describes this work in a white paper: [MX Pandemic Aftershocks Examining CA Healthcare Utilization During Covid19.pdf (netdna-ssl.com)](https://netdna-ssl.com)
access to the state’s prescription drug monitoring program (PDMP) in workflow friendly ways (e.g., North Carolina). A smaller number of states use an HIE to communicate other reportable conditions back to clinicians, such as a prior overdose, infectious disease diagnosis, or a high lead level screening (e.g., Washington, D.C.).

Several HIE capabilities make them an effective infrastructure for communicating public health data. First, HIEs have already credentialed clinicians to access data using secure platforms. By contrast, most public health agencies that open their immunization registry directly to clinicians must require a new username and password, obtained through a separate credential verification. The more information that can be combined into a single platform such as an HIE, the easier that tends to be for clinicians. Another barrier for public health agencies in making data available to clinicians in the field is that the agencies have limited ability to verify appropriate use of patient records. By contrast, an HIE can use other data to independently verify an existing patient relationship before making information available to a clinician. Patient privacy is better projected with this step.

In addition to making patient identifiable data available to particular clinicians, a subset of HIEs is publishing reports in partnership with a DOH. The Maryland Department of Health wanted to give more detailed COVID response statistics to health care organizations than what was published on the governor’s website. For instance, the department wanted to communicate the amount of PPE available at each facility and to show local clinicians the number of daily COVID cases at the census block level of granularity. By using the HIE to publish these reports, the department could place them behind a firewall, which health care organizations could access with existing credentials. A more detailed understanding of information collected by Maryland’s DOH was helpful to those in the field, and it could be rapidly published via the HIE using existing infrastructure.

National Direction

The efforts by states to use HIE to enhance public health infrastructure overlap with those of federal agencies including the Centers for Disease Control (CDC). CDC’s Data Modernization Initiative (DMI) is a “comprehensive effort to modernize core data and surveillance capabilities across the federal and state public health landscape.” To date, CDC has not emphasized state-based or subregion HIEs in its planning. The Data Modernization Initiative Strategic Implementation Plan as of December 2021 does reference the “exchange” of data in seven places and the role of the Trusted Exchange Framework and Common Agreement (TEFCA) in one, but it does not specifically call out a role for HIEs or other data intermediaries. Our research found that HIEs are actively exchanging and enhancing the data that CDC identifies as needing to be interoperable, and in this regard federal plans and state efforts are not in alignment.

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Conclusion

The below table summarizes the frequency with which we found states relying on a statewide or subregion HIE for at least one purpose within each category. We note here the limitations of our research methodology. Most states were represented by one or two local informants. We relied on the judgment of informants that a capability was being used in their state and on their knowledge about activities in the state in which they may not be directly involved.

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of States</th>
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<tr>
<td>Reporting to public health agencies</td>
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</tr>
<tr>
<td>Use by public health employees</td>
<td>38</td>
</tr>
<tr>
<td>Enhancing data</td>
<td>23</td>
</tr>
<tr>
<td>Pushing public health data to the field</td>
<td>36</td>
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</tbody>
</table>

Table 1: Summary of Findings

As policy makers consider plans to strengthen public health infrastructure, it is important to recognize the many ways HIEs already support public health agencies. Using what are often existing infrastructures, public health agencies have launched important capabilities at low marginal cost and with low burden on the delivery system. Our research found numerous examples to show that the COVID response increased the reliance on HIEs by public health agencies. We also heard sentiments from many HIE leaders that aspire to provide more

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services to their state for public health purposes. Some HIE leaders expressed disappointment that they were unable to work more effectively with their DOH. The interviews left the distinct impression that, while many important services are live, considerable unrealized opportunities exist for states to further leverage the existing interoperability infrastructures of HIEs for public health purposes.

In a handful of states, the DOH was described as treating its HIE partner as an important part of the state’s public health infrastructure strategy (e.g., Arizona and Nebraska), and the HIE can be described as a Health Data Utility for its state. These states were more likely to have state officials/appointees on the HIE board of directors and other protections to safeguard the state’s investments. State oversight of an HIE, which operates as a public-private partnership, through legislation, regulation, and by contract would appear to strengthen the motivation for a DOH to partner with an HIE. Alternately, state agency-based HIEs, although they tend to serve Medicaid first and foremost, also have the potential to support public health agencies. In these instances, mechanisms that provide extra protections for patients/citizens may be warranted to make the HIE an attractive vehicle for public health support. Whatever the model, policy makers, public health leaders, and HIE executives should seek to learn from peer states how best to utilize HIE capabilities in support of public health purposes.

Lastly, the role of state-based HIEs is missing from the CDC Data Modernization Initiative. Yet our research found significant engagement between states and HIEs to perform the interoperability work identified as high priority by the CDC. There is opportunity for CDC to reconcile its vision to facts on the ground, particularly considering the many instances of HIEs partnering with public health agencies to support the COVID response.