https://www.chcf.org/blog/why-time-has-come-statewide-data-exchange-california/

# Why the Time Has Come for Statewide Data Exchange in California

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By Hong Truong

***Illustration: Keith Negley***

The COVID-19 pandemic has caused more than 60,000 deaths and nearly 3.7 million infections in California, a devastating event that vividly underscores the deep-seated health inequities faced by the Latinx and Black communities. The coronavirus methodically demonstrated the need for California to reengineer its health care system to eliminate those disparities and provide better care for everyone. High on the list of needed changes is a statewide health data exchange that would enable leaders to do a better job protecting public health and would provide better health care for all.

### Recent CHCF Reports on Data Exchange

To understand steps that California can take to harmonize and foster data exchange, CHCF commissioned a series of reports that focus on states with successful statewide data health networks and that explore California's particular challenges.

*Designing a Statewide Health Data Network: What California Can Learn from Other States* looks at Maryland, Michigan, Nebraska, and New York, which have successfully implemented statewide health data networks that allow all health care providers, institutions, and agencies to appropriately access and securely share patient health information electronically.

*Why California Needs a Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System* explores four areas to illustrate the toll of the state's limited HIE infrastructure: disaster and pandemic response, serving patients with complex needs, quality reporting, and value-based care. The report uncovers the shortcomings of the current HIE environment in California: clinical data fragmentation, exclusion of multiple sectors (e.g., behavioral health), and complex data exchange rules and regulations.

*Expanding Payer and Provider Participation in Data Exchange* examines a set of policy, contracting, and financing options for California to encourage increased participation in HIE. These levers range in intensity from legislation to mandating statewide HIE activities to voluntary private-public councils.

The ability to exchange data across the state would facilitate a more rapid and coordinated response from state and local public agencies and health care systems. Without it, hospitals cannot quickly report to local and state health agencies the number of admissions, discharges, and available ICU beds — information that helps identify the hardest-hit areas and guides the distribution of necessary resources. Coordinated statewide health information exchange (HIE) would automate collection of this key data, as well as information related to contact tracing, testing, and vaccinations.

The ability to share appropriate health data will be critical as the state moves forward with CalAIM, a multiyear initiative to provide a whole-person care approach to the health care needs of those enrolled in the state Medicaid program, known as Medi-Cal. The state must ensure that participating organizations can communicate data about physical health, behavioral health, and social services for Medi-Cal enrollees.

California’s HIE landscape is a patchwork of different types of health data–sharing networks that sometimes leave out social service safety-net providers. Their inability to consistently share health data across the entire care team results in a lack of coordinated services, delays in care, and poor health outcomes. Those enrolled in Medi-Cal, many of them people of color with complex physical or behavioral health conditions, frequently are compelled to navigate multiple care systems that do not communicate with each other. These include health, dental, and county behavioral plans, county social services, and substance use disorder providers.

California must adopt a long-term vision and take a multipronged approach to move information about individual patients seamlessly and securely across multiple health systems.

## Five Critical Steps to Overcoming Barriers to Statewide Data Exchange

There are five critical steps California can take to help overcome current challenges, support policymaking, and advance development of a statewide data exchange.

## 1. Establish strong leadership with a long-term vision and meaningful authority.

States with successful data exchanges all have strong leadership to oversee their data health networks. An effective leadership role for state government would define the government's role and authority to manage participation, data privacy, and financing. There should be a governing board with representation from the public, nonprofit, and private sectors in an effort to be transparent and inclusive. The board should have the authority to make decisions, determine priorities, and adopt mandates. All of this must be based on an unambiguous long-term vision with a plan for financial stability. This could be established with federal funds and transition over time to rely on state and/or private funds.

## 2. Start small, expand over time.

Shared health data infrastructure can be built incrementally by solving problems that confront providers from across the delivery system. For example, in its public health tracking the New York exchange sends public health lab results to providers and collects and shares demographic data. This is one of many examples of states building shared infrastructure incrementally. Starting small builds trust, demonstrates the value of an exchange, and lays the foundation for sustainability. Of crucial importance is delivering the right level of information at the right time to the patient's care team. The network must prove helpful without overwhelming participants with unnecessary information. This approach meets providers' needs while growing the network over time.

## 3. Create financing programs to support HIE and needed technology.

Many safety-net providers, particularly in behavioral health, social services, and public health, use technology that does not meet national data exchange standards or that relies on paper-based records. These practices prohibit them from participating in HIE. Providers without updated technology infrastructure are not able to exchange health data to mount a pandemic response or to adhere to CalAIM goals. The state should promote comprehensive data exchange by establishing financing programs for providers to update their technology systems or adopt new ones. Such modernization can only be accomplished with adequate funding support.

### 4. Align patient privacy rules.

Not all patient data is protected or regulated under the same protocols. Physical health data is covered by the Health Insurance Portability and Accountability Act (HIPAA), while social service organizations are not. Federal and state rules regulate behavioral health data and have stricter requirements that limit data sharing and require additional patient consent. Experts recommend aligning California privacy laws with federal laws to facilitate the data flow among behavioral health and social services entities. The state should also create universal consent forms to make it easier for providers to access patient data to treat the whole patient.

### 5. Promote participation.

HIE activities require broad participation to ensure the completeness and usefulness of the exchanged data. A comprehensive data network includes many types of organizations, not just medical providers. California can use a variety of levers, such as legislation, incentives, and penalties, to engage health plans and providers from health care, behavioral health, social service, emergency response, and public health programs. Several states have passed legislation or promulgated rules to increase participation in information-sharing activities.

## Time to Act

The need for statewide health data exchange in California has never been more evident. The federal government has passed the CARES (Coronavirus Aid, Relief, and Economic Security) Act and the Coronavirus Relief Fund to help states pay for the technology needed to support HIE. Long-awaited federal rules were released last year to help payers and providers build technology systems that work together to increase information flows for better patient care. Health care organizations have traditionally operated in technology silos so walled off from one another that patient care suffers.

The pandemic demonstrated that the lack of access to relevant, reliable, and timely patient data harms public health and leads to significant loss and human suffering. The state must use its many policy tools to achieve the full potential of HIE.

Other states have effectively enabled statewide HIE to protect their residents. It is time for California to do the same.

**Related Tags:**
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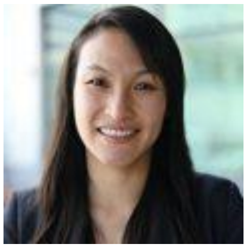

Hong Truong is a senior program investment officer for the CHCF Health Innovation Fund, where she makes mission-driven investments in health care information technology and tech-enabled service businesses, and leads CHCF's grant portfolio on data exchange and interoperability.

Prior to joining CHCF, Hong was an investor for multiple health care corporate funds, including Summation Health Ventures, the venture capital arm of Cedars-Sinai and MemorialCare Health Systems, and Kaiser Permanente Ventures. Hong holds bachelor's degrees in human biology and international relations from Brown University, and a master's degree in public health from Yale University.

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**06/01/21**

**FROM: Janis Gardner, Chair Emeritus**

**From:** "Jacqui Irwin, assembly member
**Subject: We have a message for you**
**Reply-To:** care@ourhealthcalifornia.org

Janis-

California’s behavioral health care system is failing too many of our neighbors. One in five Californians live with a mental illness, and data indicate this is expected to drastically increase as a result of the pandemic.

That’s why I authored AB 1331, which will address the fragmented network of state and local behavioral health agencies across California.

The time to do something is now. Watch my video to learn how AB 1331 would help create a statewide network of crisis care services – a historic first for Californians.

COPY & PASTE THE FOLLOWING LINK TO WATCH VIDEO:

https://youtu.be/0Gxc6Tge--A

Thank you in advance for your support,

Jacqui Irwin

Assembly member, D-Thousand Oaks

**P.S. Grassroots voices will help to make sure this bill is a priority.
Please contact your legislator after you watch the video!**