



## **Why California Needs Better Data Exchange:** Challenges, Impacts, and Policy Options for a 21st Century Health System

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## About the Author

This paper was authored by Jonah Frohlich and Eric Bartholet, managing directors; and Jonathan DiBello, consultant at Manatt Health. **Manatt Health** integrates legal and consulting expertise to better serve the complex needs of clients across the health care system. Combining legal excellence, firsthand experience in shaping public policy, strategy insight, and deep analytic capabilities, Manatt Health provides professional services to the full range of health industry players. This diverse team of more than 160 attorneys and consultants from Manatt, Phelps & Phillips and its consulting subsidiary, Manatt Health Strategies, helps clients advance their business interests, fulfill their missions, and lead health care into the future.

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The **California Health Care Foundation** is dedicated to advancing meaningful, measurable improvements in the way the health care delivery system provides care to the people of California, particularly those with low incomes and those whose needs are not well served by the status quo. We work to ensure that people have access to the care they need, when they need it, at a price they can afford.

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### ABOUT THE SERIES

This is the second in a series of reports sponsored by CHCF aimed at helping inform California decision-makers about statewide data exchange. Other reports focus on how other states have approached statewide health information exchange, and on the existing electronic health record networks, regional health information organizations, and competing infrastructure that currently exist in California.

# Introduction

The efficient, effective, and equitable delivery of care is vital to the well-being of all Californians and is necessary for a strong and vibrant economy. To achieve this state, information must easily be exchanged among medical, behavioral, social services, and public health professionals to allow them to make informed decisions that impact the lives of every resident.

Today, access to this kind of critical information is limited, with the exchange of health data confined to a subset of clinical patient information shared mostly among larger clinics and hospitals that have federally certified electronic health record (EHR) technologies.<sup>1</sup> The health information exchange (HIE) ecosystem across California is composed of a combination of direct exchange between providers, the use of national networks, and over 15 regional health information organizations (HIOs). This fragmented model delivers inconsistent and incomplete solutions that don't provide all of the critical information needed to care for the state's residents, don't provide access to all the service providers who need data, and don't scale to provide state health care leaders with the access to data they need. Coupled with restrictive, confusing, and ambiguous data exchange rules, the exchange environment does not and cannot adequately enable initiatives to improve care quality; enhance access to medical, social, and public health services; reduce disparities; and lower costs for residents, counties, and the state.

For an overview of California's HIE ecosystem and context on the different types of HIE, please see the recent CHCF publication *Health Information Exchange in California: Overview of Network Types and Characteristics*.

To address the shortcomings of the current HIE environment in California, three key data exchange issues need to be resolved:

- 1. Clinical data fragmentation.** A range of issues results in incomplete and isolated islands of patient data being available through California's current HIE ecosystem. These include a lack of full provider participation in HIE in communities served by regional HIOs, inclusion of only a subset of EHR data shared through exchanges, inconsistent participation in and data sharing between national and regional exchanges, and an array of private, exclusionary direct exchange solutions. Further, this fragmentation creates inequities in how data are accessed. There are voids in HIE network coverage in many California counties — disproportionately rural and underserved communities that often find adopting and using EHR technology to share data prohibitively expensive — generally excluding them from the benefits of HIE and leaving significant gaps in available data. The issue of fragmentation results in incomplete data sharing, creates complexity, and restricts access and use of critical data, limiting the value of the exchange platforms and eroding confidence in their completeness.
- 2. Exclusion of exchange sectors.** Regional HIOs and national networks were developed to support clinical data exchange. By and large, they do not support the broader requirements associated with organizing and delivering comprehensive clinical, behavioral, social, and emergency services for California's residents. By omitting payers and purchasers, public health, social service, behavioral health, and in most cases, emergency response providers, HIOs and national networks are not able to capture and deliver critical information vital to addressing inherent inequities in access, outcomes, and social determinants of health. As a result, providers caring for California's underresourced populations cannot see and meet all their complex needs. Additionally, the lack of adequate data sharing among all health care stakeholders, including

consumers and public and private payers, restricts their ability to use information to make informed decisions or to design new programs that would drive down cost while improving outcomes. Further, many of these sectors, especially social services, behavioral health services, and even public health departments, lack updated data infrastructure that enable electronic data capture and interoperability.

**3. Complex and onerous data exchange rules and regulations.** There are a range of restrictive, confusing, and ambiguous state and federal laws and rules that govern different types of data access and exchange. As a result, stakeholders are prevented from using and maximizing the value of available data. Worse yet, many elect not to participate in data exchange, fearing liability and the consequences associated with not adhering to privacy regulations they don't fully understand.

These three core data exchange issues are evident every day when physical, behavioral health, and social service providers, public health, and emergency response agencies seek to organize and deliver services. To better appreciate how these issues directly affect the lives of California's residents, over a dozen interviews were conducted with leaders from state and local agencies, payers, social, behavioral and clinical care providers, health care purchasers, emergency response organizations, HIE providers, and other key stakeholders. The purpose was to gain an understanding of how data exchange issues affect their ability to deliver critical services, and importantly, the impact these issues have on the people they serve. This report summarizes the views represented through these interviews, along with supporting research and insights gained through a review of other state HIE programs.

## Real-Life Scenarios: Challenges and Impacts

This report includes four real-life scenarios that highlight the shortcomings of the current HIE ecosystem, its challenges and impacts on Californians, and direction on specific actions policymakers may consider to address these issues.

### Disaster Response

California continues to see a dramatic increase in natural and human-caused disasters that impact its residents. Recent wildfires are an especially salient example, resulting in loss of life and the incalculable loss of land, homes, and personal property. Victims of disasters often find themselves evacuated to unfamiliar environments and become heavily reliant on medical and social services for care and basic necessities. HIE is a critical tool to ensure that providers have access to patients' clinical records, enabling the providers to deliver safe and appropriate treatment.

As an illustrative example, a senior resident of Northern California is evacuated due to a wildfire that engulfs his home and destroys his community, including local businesses and the clinic where he receives most of his care. He has a sore throat, headache, mild chest pain, and difficulty breathing. He is evacuated by ambulance, where he's treated for his symptoms and transported to an evacuation center in the next county. The patient is slightly disoriented, emotionally distressed, and unable to communicate his other medical conditions, including asthma and chronic heart disease, which are exacerbated by the inhaled smoke. Additionally, he is without his medications and can't remember when he last took them. The emergency responder doesn't have access to the patient's electronic medical record because the emergency medical services (EMS) medical record system is not linked to the medical record at the patient's clinic. Once the patient arrives at the evacuation center, additional treatment is provided, but the center also doesn't have access to his medical record. As a result, the local provider is reliant on a disoriented patient to

provide critical information on his preexisting conditions and the type and dosing level of his medications. The provider is uncertain about the severity of the patient's health condition and transfers the patient to an overwhelmed local emergency department as a precaution. Upon arrival, the patient is diagnosed, treated, and eventually transferred to temporary housing. If each provider had access to the patient's clinical record, the patient would have received better care, avoided a costly and stressful emergency room visit, and the burden on critical health care emergency infrastructure during a natural disaster would have been reduced.

Each year, natural and human-caused disasters including wildfires displace hundreds of thousands of California residents and cause billions of dollars in damage. In 2020 alone, California had five of the six largest wildfires in the state's history, with 6,500 square miles burned. In the LNU and SCU Lightning Complex fires alone, an estimated 200,000 people were displaced.<sup>2</sup> As large-scale natural disasters increase in frequency and severity, the need for HIE infrastructure that enables care providers to diagnose, treat, and triage the victims becomes an even greater priority. Factors limiting the effective use of HIE in support of disaster response include:

- ▶ **Data fragmentation.** While regional HIOs have been able to demonstrate the success of their service by compiling information for residents evacuated from the 2018 Camp Fire, the fragmented HIO landscape results in vast expanses of the state not having critical HIO services, or where data are not shared between HIOs. These gaps in available clinical data impact providers' ability to properly diagnose and treat patients, resulting in higher costs, inferior outcomes, and an increased burden on critical health system infrastructure.
- ▶ **Exclusion of exchange sectors.** Most information exchange efforts today don't capture and provide access to important social services information or link medical and behavioral health data with emergency response systems. Like the gaps in clinical data, supporting the complete needs of people displaced by natural or human-caused disasters

requires access to their social services and behavioral health data so emergency responders can make more informed decisions and get disaster victims what they need.

- ▶ **Complex and onerous data exchange rules and regulations.** The issues of data access are compounded by consent requirements that may prohibit data sharing, especially for patients unable to provide written consent in an emergency.

## Pandemic Response and Public Health Reporting

The pandemic elevated awareness of the importance of robust HIE to rapidly identify, track, and respond to surges in COVID-19 cases and to mobilize resources to contain its spread and impact. Leaders need access to timely testing information from labs, providers, and hospitals to identify new case clusters and to know where critical resources such as ICU beds and ventilators are. With this information, they can coordinate responses with state and county public health agencies and providers to better direct resources where they are most needed. Managing the rollout of state-wide testing, contact tracing, isolation support, and vaccination programs similarly requires reliable and timely information so that state, county, and health care delivery system leaders can organize and coordinate their pandemic response efforts.

As an illustrative example, a woman in Los Angeles County exhibits symptoms associated with the onset of COVID-19, including a slight fever, fatigue, and body aches. She contacts her primary care physician, who directs her to get tested, self-quarantine, and continue to monitor her condition. The patient restricts her activities but has to leave her apartment to get food at a grocery store, her prescriptions at a pharmacy, and a COVID-19 test. Within days she receives a positive test result and her condition declines, with a worsening fever, shortness of breath, and pressure in her chest. At the advice of her physician, she calls for an ambulance and is rushed to the nearest emergency room. Although her conditions are considered severe, all ICU beds are filled with other COVID-19 patients,

and no ventilators are available. She is kept in the emergency room for an extended period as her condition deteriorates. Eventually, an ICU bed and ventilator are made available and her condition stabilizes, but she is required to stay in the hospital for many days to recover. Once she is stabilized, a public health investigator contacts her and tries to reconstruct where she had been and with whom she had been in proximity during her contagious period. However, over a week has passed so attempts to trace her interactions at the grocery store and pharmacy are in vain. If public health officials and emergency responders had better information about hospital capacity, she could have been triaged to a hospital with more ICU and ventilator capacity and received critical treatment sooner, and contact tracers could have had better information to inform her employer of her positive COVID test so they could take immediate precautionary steps.

In the early stages of the pandemic, the failure of the California Reportable Disease Information Exchange system (CalREDIE) — which was not designed to consume data from HIOs or EHRs at the scale needed to address a global pandemic — hampered the ability of state and local public health agencies and health system partners to understand and respond to regional COVID-19 case surges. It also highlighted a fundamental disconnect between the state’s public health and health care data systems; without accurate and timely disease surveillance information moving from the delivery system to CalREDIE, it was unclear where ICU beds were available or how ventilators and other supplies procured by public agencies should be deployed to hospitals and clinics most impacted by local surges. And without efficient, automated mechanisms for hospitals to report admission, discharge, and transfer alerts and ICU bed availability, overwhelmed facilities were required to hand tally and manually report capacity to local and state public health agencies. Similarly, the lack of reliable information exchange infrastructure adversely impacted coordination across public health, social service, and health care providers in their implementation of contact tracing and isolation support programs. Without timely test results, contact tracers couldn’t track down infected residents before they came into contact with others in their

communities. And without a reliable means for public health agencies to rapidly access social services information to understand what services infected residents were using, it was difficult to understand their basic needs and to mobilize services such as meal and medication delivery to support them once quarantined.

The inability for state and county leaders to access reliable, real-time data also hinders the state’s vaccination strategy and its ability to identify and address disparities in how COVID-19 response programs are implemented. The lack of real-time data exchange between state and county agencies, health care providers, and mass vaccination sites is also restricting the ability of state and local officials and providers to understand vaccine supply and demand needs and coordinate an immensely complex logistical challenge.

These challenges have had a disproportionate impact on racial and ethnic minorities — particularly Black, Latinx, and Native American communities — that have suffered from higher infection and mortality rates.<sup>3</sup> Adequate HIE infrastructure would enable leaders to understand these disparities so they could better deploy resources to ensure that critical services, ventilators, and vaccines could be more efficiently and equitably allocated.

California has experienced a myriad of challenges associated with the COVID-19 crisis, including undercounting of COVID-19 cases that likely led policymakers and health care providers to base decisions on inaccurate information.<sup>4</sup> Although it is difficult to calculate the entirety of the impact these gaps have had on the care delivered to California’s residents, with over 3.5 million documented COVID-19 cases and more than 50,000 deaths in the state at the time of this writing, the potential impact that the current fragmented data exchange model has had is substantial.<sup>5</sup> The core underlying issues include:

- ▶ **Exclusion of exchange sectors.** CalREDIE and the California Immunization Registry (CAIR) systems were not designed to connect, consume, and incorporate health information from HIOs or directly from EHRs at the scale needed to tackle

a global pandemic. As a result, critical information is not readily accessible, including timely tracking of new cases, hospital emergency department and ICU bed capacity, data that would allow public health officials to identify disparities in how the virus impacts different communities, or how resources are being deployed. Without these data, public health officials are challenged in organizing their response to the crisis and don't have a complete picture of where to direct critical resources to support overwhelmed local providers. Further, a lack of available social and behavioral health data restricts public health officials' ability to identify and address gaps in social and mental health supports. These are especially critical for those most in need, including underserved communities and residents seeking social services — among them food and housing — while self-isolating.

- ▶ *Complex and onerous data exchange rules and regulation.* Navigating complex data exchange regulations and patient consent requirements can be difficult to obtain and manage, particularly during an emergency and a fast-paced pandemic, prohibiting sharing of certain types of information.

## Serving Patients with Complex Needs

Patients with serious medical and behavioral health conditions and social needs are among the most underresourced residents in California. They typically receive care from networks of unaffiliated primary care, specialty care, behavioral health, and social service providers, each of whom is providing services tailored to aspects of the patient's unique needs. To deliver the safest and most effective care, providers need to coordinate care and have access to information from all the providers serving their patients.

As an illustrative example, a man being treated for schizophrenia also has diabetes and a history of chronic housing instability. His co-occurring conditions have hampered his ability to remain employed, and without consistent treatment to control those conditions, he often finds himself losing access to

affordable housing. He receives most of his care from a mental health provider who helps manage his schizophrenia and maintains his record on a protected electronic charting system. His primary care provider helps manage his blood sugar levels through medication and insulin therapy and maintains his physical health record in a separate EHR. Neither provider can access the other's records nor are they aware of the complete set of medications prescribed. When a new schizophrenia treatment causes metabolic side effects that exacerbate his diabetes, the man is hospitalized and experiences serious complications including impaired vision and potential nerve damage. With his worsened medical condition, he is unable to retain employment and is forced to seek supportive housing, but the housing support specialist doesn't have access to either his behavioral health or his physical health records and underestimates his needs, slotting him in a lower-priority tier for housing placement. Without a coordinated care team supported by shared access to his complete record, the man struggles to receive the care he needs to regain stability and effectively manage his health. If his mental health, primary care provider, and housing support specialist had complete access to his records, they could have worked together and made more informed decisions to address his social, behavioral health, and clinical needs so he could manage his co-occurring conditions and continue working and living in a low-income housing unit.

Tragically, an estimated seven million people in California have multiple chronic conditions and account for almost 60% of over \$367 billion that the state spends on health care; approximately 8%, or 3.2 million, have substance use disorders; and 4% of California's population, or 1.5 million people, have a serious mental illness.<sup>6</sup> People with a serious and persistent mental illness and chronic disease have a reduced life expectancy — sometimes on the order of decades.<sup>7</sup>

The current HIE ecosystem is not sufficient to support the effective management of patients with complex conditions. The core issues include:

- ▶ **Data fragmentation.** Smaller safety-net providers often lack adequate infrastructure, such as a certified EHR, that would allow them to participate in data exchange. Since the cost of participating can be prohibitive for some, secure information sharing is often limited to larger health systems and clinics, resulting in a lack of coordination across the full clinical care team.
- ▶ **Exclusion of exchange sectors.** Behavioral health and social service providers also typically lack adequate technology infrastructure, including EHRs that would allow them to participate in data exchange. These providers often have limited resources and were ineligible to participate in prior national programs including HITECH (based on the Health Information Technology for Economic and Clinical Health Act), which incentivized the adoption of certified EHR technologies. As a result, current data exchange is mostly limited to the physical health record and does not include mental health, substance use disorder (SUD), or social services information.
- ▶ **Complex and onerous data exchange rules and regulations.** Restrictive and often confusing federal and state data privacy policies regarding appropriate use of patient information, including SUD data, often prevent access or create significant enough concerns about liability that providers elect not to connect to or access information from other providers even when it is available through a national or regional HIO network.

## Quality Reporting and Value-Based Care

Value-based care initiatives, including quality improvement and price transparency programs, can significantly drive down costs and deliver better clinical outcomes.<sup>8</sup> Data exchange can support these initiatives by providing payers and health care purchasers with greater access to information necessary to assess and measure quality of care and to validate models that decrease unnecessary costs and improve outcomes. Improving access to clinical, cost,

and quality information can also empower consumers to make more informed decisions regarding their care choices.

As an illustrative example, a woman is diagnosed with early-stage glaucoma that can be treated by a moderate-risk surgical procedure. Her insurance plan covers 80% of the cost for the procedure. The patient receives a referral, but the surgeon she is referred to has a four-month wait, and she needs to have the procedure done as soon as possible. She searches online for other specialists in her area and identifies several. Unable to differentiate them based on quality and cost, and relying solely on consumer ratings, she selects one with favorable reviews who is close by and can schedule her quickly. After the procedure is completed, her vision is mostly restored, but within months she experiences vision distortions that grow progressively worse. She requires a second surgery, but her insurance carrier is hesitant to pay for a repeat procedure that should have been unnecessary. After lengthy negotiations and appeals, they agree to cover the service, but her copays and deductibles far exceed her budget, and she is forced to establish a multiyear payment plan difficult for her to afford. With better information on quality, her insurance carrier could have developed networks of providers with demonstrably better outcomes, providing improved service to its customers and potentially lowering the cost of care. And if she had access to her own clinical information and a more complete picture of cost and quality information up front, she could have made a more informed decision resulting in a better outcome and not leaving her with crippling debt.

California spent \$367.5 billion on health care in 2016, representing approximately 14% of the state's economy.<sup>9</sup> Most of that spending has no correlation to outcomes; two-thirds of health care payments in the US are not tied to quality of care or value.<sup>10</sup> The impact to the state is significant. General fund spending alone on Medi-Cal and CalPERS (California Public Employees' Retirement System) in 2019 totaled \$101.7 billion and represented over 17% of the state's general fund expenditures.<sup>11</sup>



Quality reporting and value-based care initiatives are often impeded by a lack of access to clinical outcomes data that patients and payers including Medi-Cal, CalPERS, and private insurance companies can understand and use. These challenges are primarily driven by the following issues:

- ▶ **Data fragmentation.** Lacking access to clinical information from all providers who deliver care, patients, payers, and purchasers have an incomplete health record and can't make fully informed decisions based on quality, outcomes, and costs.
- ▶ **Exclusion of exchange sectors.** Regional HIOs and national networks are primarily designed to share clinical data between providers. Consumers, health

care purchasers, and health plans generally don't have access to them. As a result, basic information a consumer would need to make critical health care decisions based on cost and quality is not made available. Health care purchasers and health plans often must rely on administrative data from claims rather than clinical data to understand outcomes. Claims are useful to document prices paid for services or to indicate that an encounter took place, such as a vision screening or a glaucoma surgery, but they cannot be used to understand the outcome of that visit or procedure. Without access to clinical data, purchasers and health plans are limited in their ability to detect and address disparities in outcomes, identify best practices, develop new innovative payment models, organize and manage

**Table 1. Core Challenges to HIE in California Across Four Scenarios**

	DISASTER RESPONSE	PANDEMIC RESPONSE AND PUBLIC HEALTH REPORTING	SERVING PATIENTS WITH COMPLEX NEEDS	QUALITY REPORTING AND VALUE-BASED CARE
<b>Clinical Data Fragmentation</b>	Inaccessible clinical data from providers without certified EHRs results in incomplete information for displaced patients.		Lack of adequate infrastructure, including certified EHRs and funding for many safety-net providers that would allow them to share data and help coordinate care.	Incomplete clinical data available to patients and payers to inform cost, quality, and outcomes.
<b>Exclusion of Exchange Sectors</b>	Emergency response systems do not have access to electronic behavioral and social service data needed to support displaced and affected residents.	CalREDIE and CAIR were not designed to consume and provide complete and real-time clinical data on the scale necessitated by COVID-19 response. Behavioral health and social service data are not available in real time, restricting public health and provider capabilities to identify and address behavioral and social needs.	Behavioral health and social service providers typically lack adequate technology, including EHRs, that would allow them to participate in information exchange and to access physical health data.	Patients, payers, and purchasers lack access to complete clinical data, limiting their ability to identify high-quality providers, develop innovative payment models based on clinical outcomes, and manage provider network quality.
<b>Complex and Onerous Data Exchange Rules and Regulations</b>	Navigating complex data exchange regulations and patient consent requirements can be difficult to obtain and manage, particularly during an emergency and a fast-paced pandemic, prohibiting sharing of certain types of information.		Lack of understanding and liability concerns, especially for organizations without the capacity to interpret state and federal law, result in entities choosing not to participate in HIE or to access information available to HIOs or other providers.	

high-quality provider networks, or just understand fundamentally which providers they contract with deliver high-quality care.

Table 1 on page 9 summarizes the major challenges and actors implicated in the four scenarios above.

## Key Actions for Consideration

Health information exchange can provide critical capabilities to mobilize data so they're available when residents are displaced by natural disasters. The COVID-19 pandemic also demonstrated the need to build more robust information exchange capabilities, enabling public health response to coordinate statewide testing, supports, and vaccine efforts. Comprehensive HIE that extends beyond the exchange of physical health data is also needed to assemble a complete patient record, so a provider serving a person with complex needs can see all the patient's medical, behavioral, and social service information and can develop care plans that take into account all the patient's needs. And value-based payment programs are dependent on clinical information exchange to empower patients and purchasers to make better-informed decisions.

Each of the scenarios described in this report evokes a complex set of HIE challenges, and highlights significant gaps in California's information exchange capabilities that have serious implications for residents, the providers who care for them, and the public and private agencies who cover and support them.

Interviews with numerous stakeholders and extensive research into other states' HIE activities suggest that comprehensive statewide HIE is best supported when a range of policy, contracting, and financing levers are used together to advance data exchange. States with more robust HIE have established strong leadership structures within government to guide policy and program actions, address HIE gaps, and overcome barriers. In most cases, these states have enacted new

laws, promulgated rules to encourage or require HIE, established HIE contracting provisions in public purchasing programs, and directed state investment in technology, services, and training. The following is a summary of challenges in California's HIE ecosystem and actions policymakers could consider to address them.

## Align Leadership Across State Purchasing, Regulatory, Health, and Social Service Agencies

Beyond the three common problems of clinical data fragmentation, exclusion of exchange sectors, and complex and onerous data exchange rules and regulations, these scenarios also show that a wide range of sectors and organizations need to participate in HIE to provide "whole person" care. In order to address these challenges across the scenarios, rule-making authority and policy levers for financing and incentivizing participation must sit across many state departments. Research into states with more robust HIE suggests that strong state leadership and a governance structure empowered to align the various policy, contracting, and financing levers at its disposal can significantly advance HIE.<sup>12</sup>

- *Establish an office and advisory board within state government charged with advancing HIE through alignment of financing, contracting, and policy levers across state agencies.*

California could establish an office within state government charged with establishing the state's vision, goals, and priorities for advancing health information exchange. The office could be endowed with rulemaking authority that aligns regulatory, contracting, licensing, and financing levers available to state government agencies to advance HIE. It could also be charged with developing recommendations to harmonize state law that conflicts with federal law. And statute could direct the office to develop clear HIE guidance and technical assistance to state agencies and stakeholders, building upon existing efforts including the State Health Information Guidance issued by the California Health & Human Services Agency.<sup>13</sup>

The office's authority could be crafted to be broad enough to direct health plans funded through publicly purchased coverage programs (e.g., Medi-Cal, Covered California, CalPERS) and both health plans and providers licensed by the state to ensure consistency in the implementation and enforcement of HIE rules the office enacts. The office's authority could also allow it to define consistent HIE contracting requirements so that the purchasing power of state agency procurements can be aligned to direct contractors to consistently carry out state priorities. The authority could extend to health plan and provider licensing agencies to help ensure HIE rules are enforced and followed by entities they oversee that provide coverage and deliver services. And the office could guide and help secure state and federal financing streams to fund HIE infrastructure, services, and training.

To get input from experts and affected stakeholders, the office could be guided by a multistakeholder Health Information Exchange Advisory Board that brings together state and county agencies; physical, behavioral, and social service providers; consumers; and others with HIE expertise. The board could be charged with developing recommendations to the office's leadership regarding state HIE goals and strategies, prioritizing information exchange initiatives and programs, and offering input into how the state can effectively utilize policy, financing, and contracting levers at its disposal. The board could also review and provide feedback on the office's recommendations specifying where California health and safety codes could be updated to overcome information exchange barriers.

## Address Data Fragmentation

While millions of patient health records are shared electronically in California every day, significant gaps in the state's HIE ecosystem remain, especially in rural regions and underserved communities. Many regional HIOs have emerged but still only serve a fraction of the state; the nine largest regional HIOs support exchange in 35 of 58 counties in California, representing approximately 22 million of the state's 40 million residents.<sup>14</sup> HITECH incentives and state and

federal grant programs have supported some provider participation in HIE, but it has not been enough to encourage all hospitals and clinics to electronically share health information. A combination of state mandates and provider HIE participation requirements in public and private purchasing programs in Maryland, New York, North Carolina, and others have been used to advance HIE.

► *Establish statewide health information exchange requirements, incentives, and penalties to encourage broad HIE participation by health plans and providers in health care, social service, emergency response, and public health programs.*

Despite billions that have been spent to implement certified EHRs through HITECH, many providers still do not share information. The state could pass new laws requiring hospitals, providers, and health plans to participate in HIE activities that meet specified state health care, public health, social service, and emergency response goals. Requirements could be designed by the new office with input from its advisory board that align with and reinforce federal rules established under the 21st Century Cures Act and elsewhere.<sup>15</sup> A number of other states have passed legislation or promulgated rules requiring participation in information-sharing activities and can serve as examples to California.<sup>16</sup>

States with more comprehensive HIE have used multiple policy levers, like mandates with contracting and financing levers, to stimulate participation in data-sharing activities.<sup>17</sup> To complement HIE participation requirements in California, state purchasers including the California Department of Health Care Services (DHCS), Covered California, and CalPERS could establish contracting requirements with payer partners requiring their provider networks to participate in HIE activities that meet state policy goals. Those could be reinforced with incentive programs, including the Medicare Merit-based Incentive Payment System and Medicaid performance improvement programs that can leverage state and federal funding to encourage HIE participation.<sup>18</sup> They could also be coupled with quality collaboratives, such as the Integrated

Healthcare Association’s “Align. Measure. Perform.” program, or Blue Cross Blue Shield of Michigan’s Collaborative Quality Initiatives.<sup>19</sup>

Quality and value-based payment programs could leverage the Health Care Payments Data Program (HDP) of OSHPD (California Office of Statewide Health Planning and Development). The HDP will collect administrative health care data from health plans and other payers in California and support greater health care cost transparency to inform policy decisions regarding the provision of health care and to reduce health care costs and disparities.<sup>20</sup> Ultimately, using the full complement of policy, financing, and contracting levers could help provide more complete information to consumers — in alignment with new federal rules requiring health plans to provide health information to their members — to help them make more informed choices about providers and provide health plans with better information to develop value-based payment programs and high-quality networks.<sup>21</sup>

## Address Exclusion of Exchange Sectors

Federal HITECH programs omitted thousands of behavioral health and social service providers, leaving them without electronic recordkeeping systems capable of sharing mental health, substance use, and social service information with other providers. Pilot programs including California’s Whole Person Care Section 1115 Medicaid waiver have demonstrated that these providers can be supported through community information exchange initiatives. But the demonstrations are temporary and insufficient on their own to meet the needs of all providers that support the complex needs and address disparities of millions of patients and families in California.

► *Establish financing programs that support statewide physical, behavioral, and social service data exchange.*

Most behavioral health and social service providers don’t use information systems that can meet national data exchange standards, and many continue to

use paper-based records. And while most hospitals, providers, and specialists now have certified electronic health records (EHRs), many still don’t routinely exchange information with other providers who care for the same patients. As a result, critical physical, behavioral, and social service information remains locked in siloes, inaccessible to the broader care team, public health agencies, and emergency responders. California policymakers could establish financing programs to help providers implement robust information technology to support the secure sharing of data with other physical, behavioral, and social service providers and public health agencies. And it could direct the new office and its advisory board to identify financing streams and align program requirements to maximize their impact.

The state could model the program after the 2009 federal Health Information Technology for Economic and Clinical Health (HITECH) Act that established funding for primary care providers, specialists, and hospitals to implement EHRs that can securely share information.<sup>22</sup> That program enabled the migration of the industry’s antiquated paper-based clinical recordkeeping system to interoperable electronic health records. No such program exists for a large segment of behavioral health and social service providers. The state could leverage existing funding sources, such as the 2004 Mental Health Services Act, which funds a broad continuum of service needs including improving or replacing behavioral health provider technology systems.<sup>23</sup> California could also build upon and significantly scale up successful state programs, including CalHOP (California Health Information Exchange Onboarding Program), which invested \$5 million in California general fund resources and drew down \$45 million in federal funding to help providers connect to HIOs.<sup>24</sup>

As DHCS establishes CalAIM (California Advancing and Innovating Medi-Cal) program, it could consider ways to tap into Medicaid Enterprise System (MES) funding to leverage and reuse technology that can advance HIE and expand programs, such as Medi-Cal’s Section 1115 waiver Whole Person Care demonstration that supported behavioral and social

service information exchange, including the successful Alameda County Community Health Record program.<sup>25</sup> Those efforts could be significantly reinforced with requirements that public payers, including DHCS and CalPERS, Covered California, and state-licensed commercial health plans, expand HIE incentive programs to include behavioral and social service providers. All these efforts will require significantly more state investment than has been made to date to fill the significant information exchange gaps that exist today.

► *Upgrade California's public health and emergency response information exchange infrastructure.*

The pandemic laid bare the inadequacies of California's public health information exchange infrastructure in responding to the pandemic. CalREDIE was not designed to handle data on the scale necessitated by COVID-19, and the California Immunization Registry (CAIR) was designed primarily to track childhood immunization records, not a statewide vaccination campaign for all residents. The state's ongoing experience with wildfires has also made clear the need to expand state and local EMS data exchange infrastructure. Policymakers could leverage federal funding from the Centers for Disease Control and Prevention (CDC), supplementing them with state resources to upgrade state and county surveillance, reporting, and emergency response systems. Publicly funded purchasers could also incentivize providers to share patient information with emergency response, public health, and syndromic surveillance systems. Upgrading state and county infrastructure and designing incentives for providers to send patient information including race, ethnicity, and demographic data would provide county and state leaders with data to identify outbreaks; monitor the efficacy of pandemic and emergency response; organize statewide programs to manage the spread of COVID-19, including vaccine distribution; and identify and address disparities. Funding could include training for public health agency staff and providers on the use of the required infrastructure to ensure a capable and well-equipped workforce.

## Overcome Complex and Onerous Data Exchange Rules and Regulations

The four scenarios described above require access to some combination of physical and behavioral health and social service data, which are subject to a large and complex set of federal and state privacy laws, most of which were not written with data exchange in mind.<sup>26</sup> Harmonizing state law with federal privacy and security rules and providing more clarity about what is required to support informed consumer consent could foster greater participation in HIEs and lower legal barriers to accessing and using data available through HIE.

► *Harmonize state privacy rules and regulations with federal law.*

Many state laws were written before electronic data sharing was even possible, making it difficult for organizations to interpret and understand data-sharing implications, including the threat of liability for violating rules they may not be aware of. California could enact law based on recommendations made by the new office and its advisory board to identify conflicting and ambiguous state health information privacy and security rules, and update California health and safety codes to harmonize them with federal law.

► *Establish statewide, universal consent policies.*

The lack of a comprehensive and consistent state privacy and security framework and universal informed consent policies that supports physical, behavioral, social service, and public health information sharing impedes data exchange. The byzantine privacy landscape and lack of clear and consistent data-sharing and consent policies result in institutions exhibiting justifiable protectionist behaviors, short-circuiting efforts to exchange vital information. New state law could direct the new office and its advisory board to define requirements for a statewide universal informed consent model and set of standard consent authorization forms. And by applying contracting and licensing levers at their disposal, state agencies can incentivize

and require their use by contractors and licensed entities. New law could also require participation in CTEN (California Trusted Exchange Network) to support exchange between California HIOs and national networks, and adopt the California Data Use and Reciprocal Support Agreement (CalDURSA) as part of a broader set of data-sharing and consent policies.<sup>27</sup>

Establishing a universal statewide consent model would reduce the legal burden and encourage HIE participation by providing clarity and bright lines that describe allowed and prohibited HIE activities and data uses.

### Health Insurance Portability and Accountability Act

Physical health information exchange is subject to the Health Insurance Portability and Accountability Act (HIPAA), which envisions disclosures of protected health information between “covered entities” that include health care providers and payers. Federal rules including 42 C.F.R. Part 2 and state rules including the California Health & Safety Code 11845.5 regulate certain forms of behavioral health data with narrower allowances for data sharing that require more rigorous patient consent. Homeless Management Information Systems (HMIS) data is subject to the Housing 2004 HMIS Data and Technical Standards, which permits disclosure of data only among housing agencies.

## Conclusion

To achieve the promise of health information exchange, California needs bold leadership, a clear vision, and measurable goals that guide policy and financing decisions and programs that enable comprehensive statewide data exchange. The scenarios outlined in this report highlight the impacts that fragmented HIE has on the lives of Californians and the challenges providers face when serving them. To address these challenges, California could enact a new law that establishes an office within state government with the authority to direct state agencies and to use a variety of financing, contracting, and policy levers to stimulate HIE infrastructure and programs. But the state will need to provide enduring leadership and financial support to incentivize the adoption and use of technology that securely connects providers to each other. Whether it is to address the challenges of managing a pandemic, responding to a natural or human-caused disaster, supporting the needs of our most underresourced residents, or helping advance quality and value-based care for all Californians, the time for strong state leadership to coordinate collaborative efforts to overcome them is now. There has never been a better or more pressing time to act.

## Appendix. Interviewees

ORGANIZATION	INTERVIEWEES
Alameda County Care Connect	Jennifer Martinez, MPH, program development director
California Department of Public Health	Scott Fujimoto, MD, public health medical officer Daniel Daugherty, PhD, research scientist manager Sandra Shewry, MPH, MSW, former acting director
California Emergency Medical Services Authority	Leslie Witten, MA, chief of the office of health information exchange
California Public Employees' Retirement System	Heather Readhead, MD, MPH, medical director of clinical programs
Cedars-Sinai	Darren Dworkin, senior vice president of enterprise information services and chief information officer
Covered California	Alice Chen, MD, MPH, chief medical officer James DeBenedetti, director of plan management Isaac Menashe, MPP, associate director, evaluation & research Margareta Brandt, MPH, manager of quality improvement
Integrated Healthcare Association	Jeff Rideout, MD, president & chief executive officer
Northeast Valley Health Corporation	Stephen Gutierrez, chief information officer
QueensCare Health Centers	Arnel Mendoza, director of information systems
SacValley MedShare	Elizabeth Steffen, MBA, executive director
Sierra Vista Hospital	Mike Zauner, MBA, chief executive officer

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