Expanding Health Information Exchange to Advance Health Equity in California

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BACKGROUND

Health Information Exchanges (HIEs) enable health care providers to access patient information from outside of their practice or health system to deliver informed care. The COVID-19 pandemic further emphasized the value of HIEs by enabling public health agencies to precisely target interventions among vulnerable populations for vaccination efforts, contact tracing, and early disease outbreaks. HIEs facilitate the real-time and secure exchange of physical health data to enhance care coordination, reduce health care cost from duplicated services, and effectively respond to public health emergencies. However, HIEs typically exclude behavioral health and social service agencies from participating in this data exchange. California does not have a statewide HIE. Instead, data exchange in California is fragmented and primarily advantageous to health systems operating on the same Electronic Health Record (EHR) or participating in a regional community-based health information organization (HIO).

This report leverages research and evidence briefings to inform California's next steps for achieving statewide data exchange. By understanding past failures and learning from the success of other states, California can leverage policy and funding opportunities to advance health equity in the state.

California's Past Opportunity

The HITECH ACT of 2009 set aside billions in federal funds to incentivize the implementation of EHRs. HITECH successfully increased hospital adoption of EHRs throughout the country from this legislative effort, and intended to promote data sharing from this investment with the creation of HIOs. California uniformly adopted EHRs, however, the formation of HIOs was fragmented and the effects persist today. Early effort from the state government to standardize and coordinate HIO development in California was challenged by the state's local markets. Specifically, private health systems in the state were able to afford robust EHRs which simultaneously served as an exclusive HIO within the health system. As a result, safety net clinics and small physician practices were at a disadvantage and therefore lacked early access to robust EHRs and HIOs.

As an alternative to private data exchange networks, nonprofit community-based HIOs in California started to regionally develop. Manifest Medex is a regional HIO in California and also operates the technical infrastructure for some other regional HIOs in the state, such as the Inland Empire HIO, San Joaquin Community HIE, and Central Valley HIE. California has 15 regional HIOs with participants in at least 39 of the 58 counties, and data exchange clearly remains fragmented. Gaps in data exchange continues to disproportionately affect safety net systems and small physician practices serving the most vulnerable communities in California. Community health centers and small physician practices experience unique barriers for HIE

participation with local hospitals and health care systems. Large health systems prioritize data exchange within their own system, therefore unaffiliated hospitals or community based organizations are excluded. Implementing a statewide HIE would ensure connectivity regardless of where people live and receive health care in the state.

California's Current Opportunity

Expanding HIE in California would provide necessary data to support Cal-AIM, which is an ambitious multi-year Department of Health Care Services initiative aiming to implement program and payment reform to reduce health disparities and improve health outcomes among Medicaid beneficiaries. A statewide HIE positions California to advance health equity and synergize Cal-AIM goals. In addition to exchanging physical health data, thoughtful inclusion of behavioral health and social service agencies would significantly elevate these efforts.

The 21st Century Cures Act of 2016 requires health care systems to implement technology and data standards to minimize data sharing disruptions. This policy aims to improve data interoperability and prohibit information blocking, which is defined as the practice of interfering, preventing, or discouraging the exchange of electronic health information. In response to the public health threats from the pandemic, the Centers for Medicare & Medicaid Services (CMS) and Office of the National Coordinator for Health Information Technology (ONC) released new federal regulations through the 21st Century Cures Act Final Rule of 2020.

This policy window presents California with an opportunity to act in response to the federal regulation requiring expanded data sharing. Under the Final Rule, hospitals will be required to notify primary care providers of admit, discharge, transfer (ADT) patients. Additionally, there is an emphasis on increasing patient access to centralized records from all of their providers and health plans through an application programming interface (API). This federal regulation aims to increase the flow of data through delivery systems while maintaining strict privacy and security standards. California can advance interoperability by pairing strong financial incentives conditional on the strict adherence to data standards outlined in the 21st Century Cures Act.

Data standards ensure information is shared and accessed in a format that can easily be interpreted by a machine without requiring significant labor to decipher the health information exchanged. A national survey of third-party HIEs in 2016 reported moderate levels of information blocking by EHR vendors and health systems. In 2020, another survey assessed the prevalence of information blocking, and noted the most common behavior among EHR vendors was the setting of unreasonably high prices to switch vendors. Among health systems, the most common behavior was the refusal to share information due to business interests and competition related to sharing patients. California policymakers must appoint a governing board to lead the statewide effort in implementing a HIE with seamless interoperability across the state. Without strong leadership, HIE in California will remain fragmented due to the fierce competition among advanced health systems and EHR vendors. A statewide HIE would mitigate these barriers and facilitate secure data exchange to improve care coordination in the interest of patients, instead of business interests.

Perceived legal barriers continue to impede the growth of HIE. HIPAA protects the privacy of patients and permits the appropriate sharing of patient data among business associates for treatment purposes. HIPAA does not impose liability for downstream privacy breaches on disclosing entities that follow the rules, however, this potential reputational harm discourages

data exchange. Although some legal barriers persist, research suggests many perceived barriers are tractable and illusory because hesitancy to participate in a HIE appears more influenced by economic motivations than legal barriers itself. One aspect of HIPAA that genuinely complicates HIE is the ability for states to maintain privacy laws that are more strict than federal requirements. This misalignment on federal and state privacy laws have provoked concerns around liability. California has an opportunity to harmonize state privacy laws with the federal laws to minimize liability concerns and encourage statewide HIE participation.

Assembly Bill 1131 was introduced by Assembly Member Wood in February 2021, to enact legislation requiring "health plans, hospitals, medical groups, testing laboratories, and nursing facilities, at a minimum, contribute to, access, exchange, and make available data through the network of health information exchanges for every person, as a condition of participation in a state health program, including Medi-Cal, Covered California, and CalPERS" by January 1, 2023. The bill has since been amended in March 2021, with a revised emphasis on establishing a "governing board, an independent public entity not affiliated with an agency or department with specified membership, to provide the data infrastructure needed to meet California's health care access, equity, affordability, public health, and quality goals." The amended bill also requires health plans, insurers, and health care providers to collect and submit health equity data to the HIE. California must proceed with developing a strong governing board to advance the development of a statewide HIE and lead these efforts. California should leverage the existing infrastructure in the state to improve interoperability and also integrate social and behavioral health providers.

Success in Other States
Other states have been more successful than California in creating a robust statewide HIE by leveraging federal funding through the HITECH Act of 2009, for example, Nebraska and New York. States that already had a robust statewide HIE were better prepared to respond to the COVID-19 pandemic. New York's Statewide Health Information Network (SHIN-NY) was able to leverage core HIE functionalities such as ADT notifications and seamless data exchange of health data. HIE users also have the option to pay for value-added services such as predictive modeling to further support population health management. Unlike California, New York successfully leveraged federal grants to support the even implementation of regional HIOs with continuous support from the state's health agencies and governor's office. SHIN-NY is a hybrid model for data exchange, which consists of a group of HIE networks connected by a central hub acting as a data highway without storing data. New York's statewide infrastructure played an essential role in their COVID-19 pandemic response by managing lab results, sending notifications to providers when patients had positive results, tracking hospitalizations at the patient level, and supporting the coordination of social services. The COVID-19 pandemic revealed the pressing need for a statewide HIE, and other states offer many case examples on how HIE was successfully leveraged to address the needs of vulnerable communities.

Maryland also has a statewide HIE and requires all health care payers to submit claims data to the state's all-payer claims database. The claims data is then integrated with clinical health records through Chesapeake Regional Information System for our Patients (CRISP), which is the state's designated HIE. CRISP centrally stores data from the participating networks, compared to SHIN-NY acting as a data highway without storing data. This demonstrates to California that a statewide HIE can exist with varying data models, which is evident in Maryland and New York. With a statewide HIE, California can strategically leverage claims and health

records data, modeled by Maryland, to extract valuable insight for analysis and action. Maryland continues to leverage insights from claims and health records data to monitor hospital readmissions, especially among Medicaid beneficiaries. Additionally, Maryland's COVID-19 task force on vulnerable populations used CRISP to identify which populations were most at risk of COVID-19 complications through risk stratification. Outreach was conducted based on age, disease burden, COVID-19 susceptibility index, housing, and food. Vulnerable patients were offered expanded care options such as telehealth and special accommodations for in-person visits to improve access and health equity during the pandemic to avoid the surge.

More recently in January 2021, five states were awarded a total of $20 million in federal funding from ONC through the 2020 Coronavirus Aid, Relief, and Economic Security (CARES) Act to increase data sharing between HIEs and public health agencies under the Strengthening the Technical Advancement and Readiness Health Information Exchange (STAR HIE) Program. The five states include Georgia, Arizona, Pennsylvania, Kansas, and Texas. The STAR HIE Program has a clear focus on advancing connectivity between statewide HIEs and public health agencies to promote health equity. These investments have promising potential to enhance each state's capability in making well-informed and real-time decisions in the future during public health emergencies—such as fires, floods, and pandemics. Without a statewide HIE and strong governance, California continues to miss out on opportunities to strategically use federal funds and advance health equity.

EVIDENCE BRIEFING: DATA SHARING TO PROMOTE HEALTH EQUITY

On April 28, 2021, Cal-IHEA and Connecting for Better Health convened a panel of experts for an interactive discussion on data sharing to advance health equity. The session highlighted the need for a statewide Health Information Exchange in California to facilitate data exchange to improve care coordination and respond to public health emergencies. By securely collecting and sharing data related to race, ethnicity, and language, interventions can target vulnerable communities to effectively address health disparities.

Julia Adler-Milstein (UCSF), Alice Chen (Covered California), and Rhonda Smith (California Black Health Network) joined moderator Hector Rodriguez (Cal-IHEA) to discuss how a statewide HIE can improve health equity by leveraging race and ethnicity data. The panel also discussed the importance of establishing trust, and offered insights on how policy can support sustainable interoperability and data exchange. The briefing is the second of a three part series on HIE and Public Health, and is co-hosted by Cal-IHEA and the Connecting for Better Health Coalition. Watch the webinar recording here.

POLICY AND OPERATIONAL IMPLICATIONS

After spending the past decade digitizing medical records, now is the time to activate digital capabilities through a statewide HIE and advance Cal-AIM goals to improve the coordination of medical, behavioral, and social services. The COVID-19 pandemic revealed California's limited interoperability and establishes a clear use case demonstrating the need of a statewide HIE.

Data exchange may increase the flow of shared patients between unaffiliated hospitals and health systems. Instead of perceiving this as competition, the priority should be refocused on the

ultimate goal of achieving high quality patient-centered care. Sharing patients may introduce complexity for population management linked to performance reporting and incentives. This may be an opportunity for unaffiliated systems to be more intentional about coordinating care in the interest of the patient's wellbeing. HIE makes it easier for patients to switch between health care providers and obtain services out of network, which might drive competition to achieve patient loyalty based on perception of care.

California has many regional HIOs, and a statewide exchange should leverage the existing infrastructure to ensure full coverage across the state. Specifically, safety net systems and independent physician practices should be prioritized by first confirming EHR capabilities, and then advancing interoperability to fully participate in HIE. California should use federal and state grants to fund HIE participation costs among clinics and practices serving the most vulnerable communities. While federal and state funds may support up-front costs for HIE participation, California must anticipate financial sustainability and secure ongoing funds.

Challenging components of HIE are largely nontechnical—trust, provider engagement, and workflow redesign on the frontline all require strong interorganizational relationships. State leaders are positioned to harmonize state and federal laws by clearly outlining HIE guidance and offering technical assistance to minimize concerns of liability. Positive financial incentives and enforced mandates can also accelerate the implementation of a statewide HIE. Strong leadership from the state and policymakers can help California overcome these challenges and mitigate perceived legal barriers intertwined with business interests.

POLICY RECOMMENDATIONS FOR A STATEWIDE HIE IN CALIFORNIA
1 GOVERNANCE: ESTABLISH STATE LEADERSHIP
Designate an agency within the state government that is responsible for guiding policies, leading priorities, and developing recommendations to advance health information exchange. Create a multistakeholder board with representation from public and private sectors, county agencies, behavioral health, and social service providers for oversight and accountability. States with robust data exchange networks have strong leadership and direction from the state.

2 INCENTIVES: FINANCIAL AND REGULATORY
Leverage federal and state financial incentives to reduce onboarding costs associated with joining a health information exchange. Booster participation by prioritizing safety net health systems, community based organizations, and small independent practices to minimize the digital divide. Increase connectivity by enforcing mandates and penalizing organizations for information blocking due to business interests and competition.

3 DATA: COLLECT, LOCATE, AND AGGREGATE
Collect, locate, and aggregate standardized data to provide actionable insights to address health equity in real time instead of retrospectively. Prioritize the collection of race, ethnicity, and language data to reflect California's diversity and precisely target interventions with cultural humility—especially when resources are low, and disparities are high during public health emergencies. Leverage demographic and health data to support care coordination that is tailored to patient needs based on social determinants of health and socioeconomic factors.

ABOUT THE AUTHOR

Tanie Chantara is a Master of Public Health student in Health Policy & Management at UC Berkeley. Tanie's research interests include data interoperability to enhance care coordination and strategic efforts to improve health outcomes among vulnerable communities. Tanie previously worked in a safety net health system and often collaborated with clinical and non-clinical teams to design, implement, and evaluate quality improvement efforts while also prioritizing the patient experience. Past projects include piloting tailored interventions to improve hypertension equity and stratifying data to prioritize outreach to high-risk patients with complex conditions.

SUGGESTED CITATION

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