CHCF Q & A

Learning from the History of Statewide Health Data Exchange

An interview with Dawn Gallagher, former Maine director of health information technology and national expert

The COVID-19 crisis has sparked calls for a statewide health data network to assist with emergency response and public health efforts. The problem is that health data do not flow across large areas of California, access to patient records is limited and fragmented in areas where sharing does happen, and many kinds of health records are left out. (See the California Health Care Foundation [CHCF] report *Designing a Statewide Health Data Network: What California Can Learn from Other States*.)

California policymakers are taking a significant opportunity to improve the state's fragmented regional data-sharing efforts and become a model for the country. California Governor Gavin Newsom's budget proposal and the budget passed by the Legislature includes $2.5 million to develop health information exchange (HIE) leadership within the state. There is also active legislation seeking to advance HIE in the state . Together, we should use past lessons to plan and build successful data exchange initiatives for the future. But California has been down this road before, with a failed attempt to create a statewide data exchange that ended nearly a decade ago. Policymakers would be well advised to examine the factors that stymied earlier efforts.

Though HIE in California started at a regional level in Santa Cruz in 1996 (See *A Timeline of Health Data Exchange in California*.), statewide HIE efforts began in earnest just over 10 years ago. In 2009, a scaled initiative to create a statewide system of data exchange began when the state received more than $100 million in federal funding as part of the Health Information Technology for Economic and Clinical Health (HITECH) Act. From

the beginning, the program faced challenges, including a lack of guidance at the state level, federal delays in setting national standards, leadership turnover, and other organizational hurdles. California's statewide data exchange efforts would ultimately end in 2014, with the end of the Office of the National Coordinator for Health Information Technology (ONC) Cooperative Agreement funds, part of the HITECH Act that provided funding for HIE. The state's inability to overcome its challenges would eventually lead to a continuation of the mostly uncoordinated system of regional health information organizations (HIOs) that remains in place today.

We asked Dawn Gallagher, a national expert on statewide data exchanges, to outline what she learned after reviewing literature and interviewing some of the stakeholders who played critical roles in the design and implementation of California's statewide efforts from 2009 to 2014 (See below for a list of interviewees.). We share Gallagher's answers to key questions about that effort, which policymakers and other stakeholders can consider to reform HIE today.

Q *Why and how did statewide health information exchange initiatives get started in California just over 10 years ago?*

The big impetus for statewide data sharing then was the availability of $48 billion in national grants, loans, and incentives in 2009 to rapidly accelerate health data exchange from the HITECH Act, part of the American Recovery and Reinvestment Act (ARRA). The federal program provided significant funding for health care providers to implement and use Electronic Health Records (EHRs) and for states to facilitate the implementation of Health Information Exchanges where data from EHRs would be sent to and then exchanged with other providers' EHRs. To receive these federal funds, states needed to demonstrate their ability to effectively use planning

and implementation dollars to advance programs known variously as HIE and health information technology (HIT).

States were encouraged to name what was called a state-designated entity (SDE) as well as a state coordinator to lead statewide data exchange efforts. In 2009, SB 337 (Chapter 180 of 2009) charged the California Health and Human Services Agency (CHHS) or a nonprofit entity with a 22-member board to develop a plan to ensure that HIE capabilities are available, adopted, and utilized statewide so that patients do not experience disparities in access to the benefits of this technology.

The agency elected to lead an extensive and inclusive planning process and to select a nonprofit entity to serve as the SDE to deliver on the plans. Per the requirements in the statute, the board for this nonprofit entity would be made up of two legislators, two officials from CHHS, and 18 private health care industry and provider members. California issued an RFP for an SDE and two nonprofit organizations merged to form Cal eConnect, which was ultimately selected to fill this role.

Two years earlier, California's then-governor, Arnold Schwarzenegger, issued an executive order that called for "100% electronic health data exchange" within 10 years. In early 2009, the governor appointed a deputy secretary of health IT within CHHS, who ultimately served as the state coordinator and led the planning to coordinate health data exchange activities across California, participated on the SB 337 governance board, and convened an advisory board to provide guidance.

In the end, these efforts brought in more than $100 million in federal funds. California's plans relied primarily on federal funding; policymakers did not appropriate state funds for the HIE program.

Q *Cal eConnect ultimately shut down in 2012 and California was left with a patchwork of regional HIOs. What were some of the dynamics that shaped the outcome of the initiative?*
On the whole, California's approach reflected compromise and fell victim to lagging federal policies and leadership challenges.

The effort faced immediate hurdles gaining participation from stakeholders, especially from payers, who feared that they could be subsidizing a competing system and that agreements would require them to share patient data with potential competitors. The deputy secretary of health IT guided an extensive strategic planning effort with input from more than 600 stakeholders. The process resulted in a detailed strategic plan in October 2009 that emphasized consensus over regulatory authority to compel participation and compliance.

In an effort to overcome the resistance, California ultimately adopted a mostly decentralized model, which emphasized support for regional HIOs with a limited number of centralized coordination functions. It reflected a model that some other states chose for many of the same reasons. In California, the federal government awarded pass-through funds to regional HIOs to provide data exchange services locally. The data model laid out in the plan included two important components: 1) a decentralized data exchange dependent on technical standards to be set by federal regulations, and 2) a limited set of centralized infrastructure to provide shared statewide services, to be delivered by Cal eConnect.

Delays at the federal level in offering guidance on technical and operational data standards slowed progress toward developing a decentralized model of exchanges that were "interoperable," meaning that systems share the same language in order to talk with each other. With no federal standards and no clear state guidance beyond direction to access federal HITECH funds, the Cal eConnect board struggled to achieve consensus[1] about its mission.

Cal eConnect also was plagued with leadership challenges. Its first chief executive officer (CEO) left in August 2011 after about 14 months on the job. Following a long search for a new leader, the organization announced a new CEO in March 2012. Two weeks after agreeing to take the job, the new CEO withdrew. As a result, a Cal eConnect board member stepped into the role on an interim basis until a permanent CEO could be hired.

1. David Gorn, "After 2 Years of Cal eConnect, What's Next for HIE in California?," *California Healthline*, May 29, 2012.

In May 2012, after centralized services were announced but no contract was awarded to provide them, the Cal eConnect board announced that the best way to move more quickly to advance HIE in California was to turn over the programmatic work to an organization, the Institute for Population Health Improvement (IPHI) under the University of California, Davis Health System, with an administrative infrastructure equipped to handle it. UC Davis administered the regional HIO grants and provided education for providers to identify base features and standards of EHR systems.

The state also faced leadership challenges. As part of the gubernatorial transition from Governor Schwarzenegger to Jerry Brown in 2011, the original deputy secretary for health IT, who had been instrumental in the development of the strategic planning that created Cal eConnect, left state government, which created a leadership vacuum at the state level. Without enduring leadership or commitment from the state, these statewide HIE efforts essentially ended when federal funding for HIE under the HITECH Act ended in 2014.

Q *What policy decisions at the time prevented success that policymakers should reconsider today?*
According to interviewees, there were at least four key decisions that led to the dissolution of the efforts to establish statewide HIE.

First, and most critically, policymakers failed to provide clear and enduring statutory policy direction. Commitment to data exchange changed with each administration. Meanwhile, the state legislature gave little direction about how statewide HIE would benefit Californians if it were implemented well or how to achieve the goals, objectives, and milestones related to the federal funds that the state received. The California legislature never formally endorsed the program's strategic and operational goals. What's more, a new governor and his team did not embrace HIE as a priority. This — combined with no enduring statutory guidance — doomed the program to failure.

Second, the state relied on the federal government to implement national standards, and when the standards did not materialize in the time frame envisioned, state leaders did not step up to address that void.

Third, state leaders in charge of HIE were never granted authority to regulate HIE participation and the exchange of data. CHHS created a deputy secretary for health IT position to be a convener and facilitator of HIE efforts. The law that required CHHS to apply for federal funding did not explicitly give CHHS regulatory authority over the HIE program. The authority over HIE participation was based on individual participant agreements, which were entered into voluntarily.

Finally, the program relied exclusively on federal funds, with no plan to achieve financial sustainability with state and private funding over the long term. Unlike most states that developed statewide HIEs, California did not invest state dollars in starting or sustaining the health data exchange. The law that created Cal eConnect established a dedicated HIE fund but stated that the fund would consist only of federal funds, private contributions, and revenues generated from self-sustaining participant fees. When federal funding ended in 2014, California's efforts to enable statewide HIE efforts ended as well. Outside of California, some states that established strong state leadership with state financial support were able to sustain their programs after dedicated HIE federal funding stopped.

Q *You also wrote a report for CHCF about lessons learned from states that have been successful in implementing statewide HIE. What are some lessons learned from that research that you can apply to these challenges?*
A critical lesson from that work is that states with successful HIE initiatives took a comprehensive, statewide, long-term view in developing their programs. They use a mix of funding streams, including federal, state, and participant fees. HIEs that have relied on federal funding alone have not been sustainable. Investing state funds alongside federal and private funds demonstrates a state's commitment to health data exchange and can produce better results, as public and private entities both have a stake in the outcome.

Another lesson is the importance of strong state leadership in setting a clear vision and priorities. That leadership requires rulemaking authority, contractual enforcement ability, and/or a way to compel the exchange of data statewide. It also requires the state's Medicaid agency

to be closely involved in the leadership structure as a requirement to apply for and receive federal funding for HIT and HIE projects.

Q *Nearly a decade after the end of the effort to establish statewide data exchange, California policymakers and stakeholders are now trying again. Why should they expect things to work out differently this time?*
Several factors make this moment much more promising than a decade ago. For one thing, the technology landscape is vastly different than it was when the HIE program started in 2009. Then, less than a quarter of providers in California had adopted EHRs whereas in 2017, that figure rose to over three-quarters and 97% of California hospitals reported using certified EHRs. What's more, as of February 2020, more than $1.7 billion in federal incentive payments had been made to California, contributing to the significant growth of EHR use and data exchange.

Although the federal government did not issue technical and operational standards for interoperability between EHRs before its grant program ended in 2014, the Office of the National Coordinator for Health Information Technology and CMS jointly issued rules in 2020 that are changing the HIE landscape in broad ways. The rules require health plans and systems to exchange patient data without blocking information from other providers and require certified EHRs to be interoperable. CMS rules also require Medicare, Medicaid, and other federal payers regulated by CMS to allow patients easy access to their claims and clinical data within the claims, using an electronic device of their choosing, through what is known as a patient access application programming interface (API). These mandates will require Medicaid programs, public marketplaces, health plans, and payers in California to implement new systems and standards that will expand data exchange statewide.

Unlike a decade ago, public and private stakeholders increasingly understand the urgent need for data exchange. The COVID-19 pandemic has brought to the forefront the lack of statewide data exchange for emergency response and public health. Major state initiatives, such as the California Advancing and Innovating

Medi-Cal (CalAIM) program, propose broad reforms to delivery systems, programs, and payments across the Medi-Cal program, including the integration of social determinants of health, behavioral health, and clinical data. The person-centric care envisioned can only be accomplished with advanced HIE that connects patients and their entire health team.

Q *What should policymakers and stakeholders keep in mind in the future?*
As California policymakers and stakeholders discuss expanding statewide HIE efforts, substantial federal funding is available under ongoing CMS programs, as well as through the recent Coronavirus Relief Act and the American Rescue Plan Act. These funds can be used to build out public health infrastructure, HIE, HIT, and broadband in rural areas. Broadband, in particular, is a barrier to HIE expansion statewide, as it is needed for telehealth and to exchange health care records. Additionally, new federal requirements for interoperability, information sharing, and patient access provide opportunities to expand the use of HIEs to meet federal mandates while minimizing costs to individual health plans and payers, which would otherwise have to build and connect these systems on their own.

There is notable activity in the legislative and executive branches of California government, focused on providing opportunities for the state to see the original goal of statewide HIE come to fruition. The state budget includes $2.5 million to the California Health and Human Services Agency to develop a framework that includes a single data sharing agreement and common set of policies and procedures that will govern and require the exchange of health information among health care entities and government agencies in California. Two HIE bills were introduced this year, were held in committee, and can be considered again next year. Together, these activities provide an opportunity to clearly articulate a long-term vision for a statewide health data exchange and create enduring policies.

Interviewees

Linette Scott, MD, MPH
    Chief medical information officer
    Department of Health Care Services (DHCS)

Jonah Frohlich
    Managing director
    Manatt Health Solutions

Robert (Rim) Cothern
    Executive director
    California Association of Health Information
    Exchanges (CAHIE)

Mark Elson, PhD
    Principal
    Intrepid Ascent

About the Foundation

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.

CHCF informs policymakers and industry leaders, invests in ideas and innovations, and connects with changemakers to create a more responsive, patient-centered health care system.