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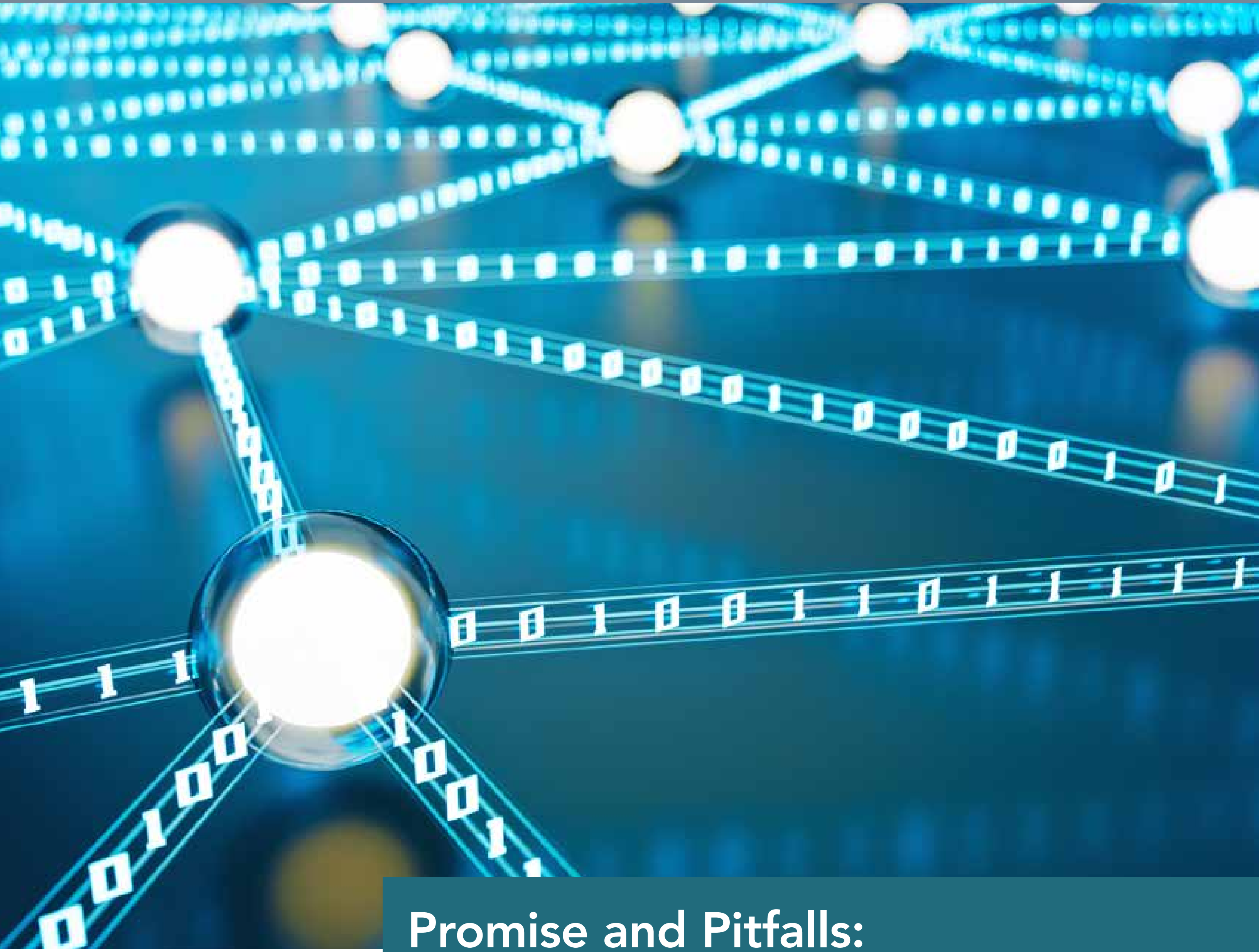

Promise and Pitfalls:
A Look at California's Regional Health Information Organizations

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About the Author

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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.

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Introduction

Each time a person comes in contact with a health care or social service entity, some amount of new data about that person is created. It could be as simple as their current weight or employment status, or as complex as a summary of a two-week hospital stay. All too often, entities must share in the care of a patient without actually being able to share much of the valuable data they hold about that patient. The inability to exchange information can result in care rife with some of the industry's worst flaws, including wasteful spending, poor coordination, and reactive rather than preventive care. This report examines the various types of health information exchange (HIE) resources available to provider organizations in California, the value that stakeholders are seeking to realize from such resources, and the specific role of nonprofit regional health information organizations (HIOs) within this landscape.

Government and private enterprise have both recognized the value of improving the ability of entities inside and outside of the health care system to easily exchange data that could inform patient care. On the government side, initiatives and incentives to promote the exchange of health information have ranged from sweeping federal efforts to more limited local ones. On the federal level, the Health Information Technology for Economic and Clinical Health (HITECH) Act, passed in 2009, has been one of the most influential legislative efforts. It has offered billions of dollars in financial incentives focused on two primary goals: first, increasing adoption of electronic health record (EHR) technologies; and second, enabling entities to share this newly created wealth of electronic health information through the creation of HIOs.

In California, EHR adoption flourished uniformly, while the growth of HIOs was more fragmented. State government efforts to standardize and coordinate HIO development across the large California marketplace were largely superseded by local market dynamics and development trajectories. Parts of the California provider market are dominated by large private health systems, many of which could afford to purchase robust EHR systems and develop private, exclusive HIOs to enable the exchange of data within their health systems. Many smaller provider entities, often members of the safety-net or independent physician communities, were left out of the more robust EHR and private HIOs and, as a result, often lacked early access to data-exchange capabilities. Some providers participated in efforts to create nonprofit alternatives to private data-exchange networks, known as community-based or regional HIOs, and at least nine such entities operate across various parts of the state today. Participation in these networks, however, has been variable and, in many regions, has not yet reached the critical mass needed to provide maximal value and achieve financial self-sustainability.

At the same time, the EHR vendor market has been consolidating, with fewer vendors serving an increasing proportion of provider organizations in the state. Certain of these vendors have created capabilities to enable robust data sharing among the customers of their own products, and also collaborated with each other to create basic data-sharing networks across their products. These developments have created new avenues for interoperability among the provider organizations using EHRs from these largest of vendors. However, they have also further marginalized provider organizations that continue to use EHRs not yet participating in these vendor-based data-sharing networks or using older versions of EHRs that do not have these data-sharing features. In many cases, these providers, especially in the outpatient setting, comprise smaller, independent physicians and community clinics that serve the safety-net population.

Hence, for independent providers and safety-net clinics, nonprofit regional HIOs remain an important means to connect and exchange data with collaborators in their communities. Because they are community-run and aim to achieve total regional connectivity through inclusivity, regional HIOs offer a healthy counterbalance to trends in the private market. They guard against any one EHR vendor or other corporate entity gaining too much control over vital data-exchange capabilities. They are also especially well suited to meet the needs of safety-net patients and the providers who care for them. For example, a regional HIO can include nontraditional service providers, such as housing agencies or substance-use treatment facilities, that are vital to the well-being of vulnerable populations but are otherwise excluded from data exchange occurring via EHRs or within private health systems. Also, the nonprofit nature of regional HIOs fosters collaboration and communication among members of competing health systems and EHRs that private-market forces might otherwise inhibit. This collaboration is especially critical for the care of safety-net patients, whose frequent use of emergency services[1] and specialty care referrals[2] makes them more likely to see providers belonging to multiple health systems and using multiple EHRs.

While regional HIOs have come a long way in California since the first one was founded in Santa Cruz in 1996, they have a long road still to travel before they fully realize their potential to help create more connected and coordinated care systems within the state. Regional HIOs currently touch an estimated 22 million lives in the state, but only about half of California's hospitals participate, and 23 of California's 58 counties still lack any significant regional HIO presence. Many regional HIOs are struggling to find sustainable financial footing and to prove their value in the face of well-funded private alternatives. Investing in their success offers a tangible path to tackling the fragmentation in California's health care system, which remains a persistent source of frustrations, inefficiencies, and disparities.

What Is an HIO?

In general, health information exchange organizations, also known as HIOs, are entities that facilitate the exchange of patient health information among the enterprises comprising a health care delivery system. They can be either community-based and nonprofit, known in California as regional HIOs, or owned and operated by a private enterprise.

Components of HIOs

No two HIOs are exactly alike, but they typically have similar organizational and technical components to enable the sharing of patient data among their participants.

Organizational Components

- **Documented data-exchange standards.** Agreed-upon formats for the exchange of health information that all participating enterprises will support.
- **Participation agreement.** Formalized relationship between the HIO and the enterprises that participate in it, including payment terms and legal obligations.
- **Data-use agreement.** Agreed-upon allowed uses of data received via the HIO — for example, limiting use to treatment purposes or prohibiting the bulk aggregation of data for insurance-contracting purposes.

Technical Components

- **Implemented data interfaces.** The HIO's means of sending and receiving patient data; sometimes includes user-interface features integrated within the existing EHR systems of participating enterprises.
- **Master patient index** *(usually)***.** Consolidates patient demographic information and unique identifiers across participating enterprises for the purpose of matching a person's clinical information held by different providers.
- **Record-locator service** *(sometimes)***.** Tracks the presence and location of specific patients' data among the participating enterprises.
- **Patient-data repository** *(sometimes)***.** Centrally aggregates, normalizes, and stores patient data submitted by participating enterprises. Many HIOs, however, just transmit patient data from point A to point B and do not maintain a persisted copy of the data.
- **Data-sharing applications** *(usually)***.** Provide various functions, including search, document retrieval, alerts, and data analysis, for the patient data that are accessible via the HIO. The most commonly included application is a web-based portal for the search and/or retrieval of patient documents. Other applications may include a subscription and routing mechanism for event notifications (e.g., inpatient admissions) or a bulk data-export capability to populate analytical databases and population-health tools.

Distinct Technology Models

Although HIOs share many components, a key distinction among many of them lies in the technology models that underlie their data infrastructures. The technology model that an HIO chooses fundamentally shapes how it collects, organizes, and exchanges its data, and therefore what use cases it can offer its members. There are three commonly used technology models: federated, hybrid, and centralized models.

Centralized Model

The centralized model operates like a hub and spoke whereby data are physically aggregated and managed centrally. An HIO is responsible for operating the centralized technology and making that clinical information available to HIO participants through it for permitted purposes agreed to by those participants.

BENEFIT

- Rich set of aggregated and consolidated patient data, enabling more analytical use cases

CONSTRAINTS

- Difficult to normalize and standardize data
- More difficult to scale
- Requires greater trust among participating members

Federated Model

In the federated model, data are stored and managed by a distributed network of HIO members. These peer organizations adopt standards and processes for sharing information under a common legal agreement among participants. If each participant adopts the ability to communicate by those standards, participants can query one another to search for information on common patients without relying on any central technology operator.

BENEFITS

- Quickly scalable
- Lower cost to implement

CONSTRAINTS

- Limited potential for data consolidation and analysis
- Lower likelihood of matching patients' data between organizations

Hybrid Model

The hybrid model is similar to the federated model in that it mostly relies on legal and governance agreements, but it has a thin layer of technology that centralizes some patient data, like identities and record-locator services. This thin layer of technology and centralized data storage serve to improve the coordination of data exchange.

BENEFIT

- More scalable than fully centralized model

CONSTRAINT

- Limited potential for use cases that require data analysis

Note: For a more detailed comparison of these technical models, refer to Douglas B. McCarthy et al., "Learning from Health Information Exchange Technical Architecture and Implementation in Seven Beacon Communities," *eGEMs (Generating Evidence & Methods to improve patient outcomes)* 2, no. 1 (May 5, 2014), accessed December 14, 2018, www.ncbi.nlm.nih.gov (PDF).

Types of HIOs

Generally, any entity facilitating some form of HIE activity, regardless of the underlying technology or governance model it uses, can be considered an HIO. Such entities can generally be grouped into one of the following categories:

1. Regional

Regional HIOs are distinct from other HIE resources in that they (1) serve defined geographical regions, ranging from a single county to an entire state; (2) are open to any health care enterprise that serves patients in a region, regardless of its business affiliations or choice of information technology vendors; and (3) are nonprofit entities primarily concerned with improving the quality and cost-effectiveness of health care in a region through greater availability and sharing of patients' health information.

Examples of regional HIOs in California include Manifest MedEx, Santa Cruz HIO, and North Coast Health Improvement and Information Network.

While regional HIOs can offer a healthy counterbalance to more exclusive private-market options for exchanging data, they do face unique constraints. Chief among them is financial sustainability. In California, most regional HIOs rely on a mix of subscription fees and philanthropic or government grants. If one or more large hospitals in a given region opts to build a private HIE network instead of participating in the regional HIO, then that HIO may lose critical subscription revenues and may be forced to raise rates on smaller entities. In turn, those entities may opt out of the regional HIO themselves, due to budgetary constraints. Ultimately, the HIO may become overly dependent on grant funding, the long-term availability of which can be unpredictable. Another challenge for regional HIOs is that many provide access to data primarily through a web portal rather than via full EHR integration. EHR integration is more costly for regional HIOs to implement, but far more attractive for busy provider users.

2. Enterprise or Private

An enterprise HIO is built specifically to meet both the financial and clinical objectives of a distinct business entity such as a hospital system, independent physician association (IPA), integrated delivery network (IDN), or accountable care organization (ACO). While these HIOs can include many different participants, such as hospitals, clinics, laboratories, and even payers, they are typically open only to organizations contractually partnered with the business entity that built the HIO. That purchasing entity has sole control over the exchange's data and available features.

Examples of enterprise or private HIOs in California include those operated by Kaiser Permanente, Sharp HealthCare, Dignity Health, and Monarch HealthCare.

While private HIOs are often perceived as presenting fewer legal and business liabilities than regional HIOs, they do have limitations. For example, provider organizations can exchange data only with other organizations that are part of the same business entity served by the private HIO. Data generated at "outside" provider organizations — at which a patient currently "in network" may have been seen in the past or in an emergency — are therefore not available. Furthermore, business entities must finance the entirety of the private HIO licensing and operations and cannot share those costs with outside organizations that might otherwise be part of and contribute financially to a more inclusive exchange, such as a regional HIO.

3. EHR Systems That Enable Data Exchange

When a single EHR system has been widely adopted in a particular region and it contains robust data-exchange features, that EHR can act in some ways like an HIO. Data exchanged through the EHR has the advantage of always being integrated directly into the EHR user interface. Provider organizations can also import patient records from other facilities that use the same EHR and have enabled its data-exchange features.

By far the most prominent example in the state is Epic and its Care Everywhere network. The Epic EHR is widely used in California by many hospital systems (e.g., Sutter, Providence, Memorial Care), academic medical centers (e.g., Stanford, UCSF, UC San Diego, UCLA), IDNs (e.g., Kaiser Permanente, Scripps Health, Cedars-Sinai), and community clinic networks (e.g., OCHIN [Oregon Community Health Information Network], Community Medical Centers).

On the downside, provider organizations cannot access patient records from facilities that use other EHRs or have not enabled their EHR's data-exchange features. Furthermore, there is no centralization or curation of patient identities, so matching rates can be poor and depend on the quality of patient demographic information provided by the two facilities attempting to exchange data. EHRs also often lack the more robust features that certain regional and private HIE networks provide, such as encounter notifications, referral management, results delivery (i.e., "pushing" patient data), or the ability to aggregate and analyze patient data in bulk across multiple EHR instances.

4. National Vendor-Sponsored

This type of HIO is funded and operated by a consortium of commercial vendors who have the shared goal of enabling interoperability among their respective health information technology (IT) products, such as EHRs. Access to the network is typically tightly integrated into each vendor's respective IT product and available to its customers with minimal custom development or configuration. Since these networks' members tend to be EHR vendors, they present benefits (data integrated directly into the EHR) and challenges (less robust features, inability to access data from facilities that have not joined the network or use a nonmember EHR) similar to the aforementioned individual EHRs offering HIO-like exchange.

Examples of national vendor-sponsored HIOs include Carequality, whose network is available to users of Epic, athenahealth, eClinicalWorks, and NextGen Healthcare EHRs; CommonWell Health Alliance, whose network is available to users of Cerner, Meditech, Evident, athenahealth, eClinicalWorks, and Greenway Health EHRs; and DirectTrust.

5. HIOs That Connect HIOs

These HIOs serve as "gateways" between other existing networks, including enterprise HIOs and regional HIOs. They provide services to normalize searches for and delivery of patient data across distinct HIOs, which can have differing data formats and standards.

Examples nationwide include eHealth Exchange and Strategic Health Information Exchange Collaborative (SHIEC).

6. Niche Commercial Data-Exchange Services

There are numerous commercial, for-profit companies that provide specific data-exchange services to medical communities. Services tend to focus on a particular aspect of care, such as the sharing of controlled substance prescribing data across hospital emergency departments (EDs), the sharing of patients' Physician Orders for Life-Sustaining Treatment (POLST) directives, or the sharing of care plans for care coordination.

Examples of vendors providing such services include Collective Medical Technologies, ACT.md, and Vynca.

High-Value Use Cases

From high hospital readmission rates to the costly ordering of duplicative tests, there are many major pain points in health care that persist at least in part because providers are unable to easily exchange information with one another about the patients they share. The ability to exchange information will only grow more important as the United States health care system increasingly embraces value-based payment models. These new models will require payers and providers to better understand which of their patients are at risk for poor outcomes and then effectively target resources, from both within and outside of the traditional health care system, to prevent those outcomes. That shift will require many new capabilities, including robust data collection and analysis, and proactive coordination with nontraditional entities that have an outsized effect on health, such as food banks and housing authorities.

The good news is that research has shown that HIOs can help providers meet these new expectations. Substantial HIO adoption has been associated in some studies with a lower rate of hospital readmissions, fewer ED admissions, fewer duplicated procedures, improved medication reconciliation, greater immunization and health record completeness, better identification of drug-seeking behaviors, and reduced total cost of care.[3] Whether California will eventually reap similar benefits depends on both increasing HIO participation rates and strengthening the capabilities of the HIOs to ensure they deliver the utmost value.

The use cases outlined in Table 1 comprise the six areas in which regional HIOs in California are focusing the majority of their efforts related to enhancing their capabilities and ultimately delivering greater value to their members. Although the different regional HIOs are supporting these use cases to varying degrees today, most have acknowledged and prioritized them as high-value goals to pursue.

Table 1. Six Use Cases of Regional HIOs in California

USE CASE / DESCRIPTION	CLINICAL VALUE	BUSINESS VALUE	DATA REQUIRED
Longitudinal patient record. HIOs can provide access to patients' health information originating from numerous sites of care either by aggregating data from across sites into a single physical patient record or by enabling retrieval of data on demand from such sites, effectively creating a single virtual patient record.	➤ Reduces potential for errors caused by poor information about allergies, prior treatments, and other information critical to clinical decisions. ➤ Increases clinicians' chances of making well-informed and evidence-based care decisions.	➤ Enables provider entities that bear financial risk to avoid poor clinical outcomes and wasteful utilization, such as redundant testing.	➤ Medication allergies; results of past laboratory, imaging, and other diagnostic procedures; previously diagnosed and treated disorders; currently or previously taken medications; and sites and frequencies of previous medical encounters
Real-time event notification. HIOs can establish "publish/subscribe" infrastructures, in which certain clinical events are always reported to the HIO, which then forwards information about the events to parties that have expressed interest in being notified of them. This mechanism can be configured on an event-specific and patient-specific basis. For example, the care-management team at a health insurer could be notified each time a high-risk patient is seen in an ED, or a primary care physician could be notified upon the discharge of one of her patients from the hospital.	➤ Enables proactive intervention, timely outpatient follow-up after ED visits and hospital discharges, and tracking of patients' attendance at important specialist visits.	➤ Enables stakeholders to divert patients to more cost-effective sites of care and to prevent costly avoidable hospital admissions by intervening proactively and arranging alternative care arrangements.	➤ Relevant health care events warranting notification may include ED visits, hospital admissions, hospital discharges, and appointments for specialist visits. ➤ Hospitals provide the data for ED visits, hospital admissions, and hospital discharges, typically via HL7 ADT ("admit/discharge/transfer") messages. The referring and/or consulting physician provide(s) the data for scheduled specialist visits.
Results reporting and document delivery to ambulatory providers. An HIO can provide a central "hub" for receiving, translating, and forwarding diagnostic results and clinical documents between hospitals and outpatient providers. In this model, each hospital and outpatient provider need only maintain a single interface to the hub, which translates the data formats appropriately to accommodate all senders and recipients. This approach replaces the highly inefficient and costly process of having each hospital and outpatient organization within a given health care ecosystem maintain numerous electronic data interfaces and perform many separate data translations.	➤ Recovers time otherwise spent by clinical and administrative staff translating, faxing, and receiving diagnostic results and clinical documents. ➤ Moves test results and clinical documents that otherwise exist in fragmented faxes into the EHR, allowing them to more easily inform clinical decisionmaking.	➤ Saves time and money spent on the staff and technologies required to maintain numerous electronic data interfaces to different trading partners.	➤ Test results and clinical documents from hospitals sent via HL7 interfaces to outpatient providers, who receive and integrate the data into their EHRs

Table 1. Six Use Cases of Regional HIOs in California, *continued*

USE CASE / DESCRIPTION	CLINICAL VALUE	BUSINESS VALUE	DATA REQUIRED
Data submission to public health agencies. For provider organizations that are already submitting lab results and immunization data via some means of data exchange, the HIO could analyze, appropriately format, and transmit these data to the public health department on behalf of the provider organizations. This model obviates the need for provider organizations to build separate interfaces to public health agencies and can automatically monitor all test results to identify and transmit those that require reporting.	➤ Ensures more complete records of patients' immunizations and reportable diseases, facilitating and improving their future care.	➤ Saves time and money spent monitoring test results for those that require reporting to public agencies. ➤ Saves time and money spent building and maintaining the separate interfaces required to complete electronic submissions, or spent manually submitting via web portals.	➤ Diagnosis, immunization, and other clinical data required by health agencies and submitted by hospitals and outpatient providers ➤ In California, the CalREDIE (reportable diseases) and CAIR2 (immunizations) public health registries receive, store, and process these data.
Data aggregation for population-health and utilization-management analytics. HIOs with data connections to numerous health care providers can receive, integrate, and normalize clinical data pertaining to individual patients in a physical data repository. These data can then be made available for analysis to interested stakeholders, either by exporting the consolidated records for all applicable patients to the stakeholders, or by providing analytical software to process the data directly on the data repository.	➤ Enables proactive identification of patients at risk for certain poor outcomes and the proper allocation of care management resources needed to avoid those outcomes. ➤ Enables the proactive identification and correction of patient care not aligned with evidence-based practices.	➤ Enables proactive identification of patients at risk for costly and avoidable outcomes and the proper allocation of care management resources needed to avoid those outcomes. ➤ Enables retrospective analysis of care outcomes and costs across a population to identify patterns associated with higher-value care.	➤ Clinical data in longitudinal patient records; claims records from health insurers
Coordinating with nonmedical providers to address patients' social needs. An HIO that is coordinating care between clinical provider organizations and delivering longitudinal patient records, event notifications, and data aggregation can facilitate "whole person care" by including data on behavioral health care, substance-use treatment, and use of social services. An HIO can add additional value by providing built-in tools for care coordination, referral management, and patient tracking.	➤ Enables care managers to better facilitate care coordination and follow up on necessary referrals for both social and medical needs. ➤ Enables providers to more effectively screen for and address the social factors that can harm a person's health.	➤ Better targets resources, both medical and social, to avoid more costly and avoidable outcomes, such as hospitalization. ➤ Better tracks and measures the cost-effectiveness of social service referrals with respect to medical utilization.	➤ Data on behavioral health care, substance use disorder treatment, and use of social services — contributed by hospitals, outpatient clinics (including community health clinics), county mental health facilities, substance use disorder treatment centers, homeless shelters, food-assistance agencies, employment agencies, and corrections facilities

Notes: *CAIR2* is California Immunization Registry; *CalREDIE* is California Reportable Disease Information Exchange; *HL7* is Health Level Seven International.

Current Challenges and Potential Paths Forward

While community-based regional HIOs have shown promise in other parts of the country, their potential has yet to be fully realized in California. Regional HIOs can certainly do more work to prove their financial and clinical value, especially in the face of steep competition from private-market alternatives, but they alone cannot close California's data-connectivity gap. Other stakeholders critical to the long-term success and sustainability of regional HIOs include the nearly 200 California hospitals not currently participating in a regional HIO, other potential participant entities, vendors whose technologies could improve HIO capabilities, state and federal officials who can clarify and revise regulations to be more supportive of data exchange, and philanthropies and other funders that can help remove up-front financial barriers to HIOs' achievement of greater scale. Table 2 describes some of the key obstacles that regional HIOs, together with other key stakeholders, must navigate in order to continue progressing toward a more connected, coordinated system of care throughout the state.

Table 2. Key Challenges and Potential Paths Forward for Regional HIOs

Limited Participation by Commercial Health Systems

CHALLENGE	POTENTIAL PATHS FORWARD
For executives at commercial hospital systems and health systems, the business case for participating in regional HIOs is often unclear. These organizations are increasingly using data-exchange services provided through their EHR vendors (such as Carequality, CommonWell Health Alliance, and Epic Care Everywhere) and investing in private HIE solutions to achieve the levels of clinical integration that they require, rather than participating in regional HIOs. In this environment, the value proposition of regional HIOs is generally decreasing and remains greatest only in fragmented medical communities, where significant provider consolidation has not yet occurred (in California, typically rural communities). As commercial hospitals and health systems are often major contributors of funding to regional HIOs, this trend may reduce available funding over time if regional HIOs are not able to provide additional services of value to these organizations or if participation in regional HIOs is not somehow mandated.	➤ HIOs can add additional services that provider organizations need and cannot obtain elsewhere, such as encounter notification, data aggregation, referral management, etc. ➤ Reduce the subscription fees charged to participating provider organizations whether through state or philanthropic subsidies, the expansion of the number of HIO participants that pay subscription fees, and/or a reduction in the overall operational costs of the HIO (perhaps by sharing the technology platform or staffing with other HIOs). ➤ Mandate or incentivize participation in a regional HIO via directives issued either by the state or payers.

Cumbersome Provider Workflow Due to Limited EHR Integration

CHALLENGE	POTENTIAL PATHS FORWARD
Access to the comprehensive patient record is often available to users of regional HIOs only via a web-based portal application, which requires clinicians to leave their EHR tool, log in to a different application, and reenter the patient's demographic data before accessing the patient's record. When a separate application is the only means for accessing HIO data, actual use of the HIO is significantly diminished. While integration of HIO services directly into the EHR is preferred, it also tends to be far more costly.	➤ Whenever possible, regional HIOs should aim to integrate their services directly into the EHR products used by HIO participants. This is especially true for ambulatory EHR products, for which the integration process is often more difficult and less well supported by the provider organizations that use them. ➤ At the same time, HIOs would benefit from an attempt to standardize the APIs and other integration features of EHR products, so that they more consistently support the existing and envisioned functionalities of HIOs. A working group of EHR vendors and HIOs could convene to address this issue, possibly in collaboration with the HIMSS EHR Association and the Strategic HIE Collaborative (SHIEC), respectively, or similar bodies.

Transition to Centralized Data Storage Models

CHALLENGE

Most regional HIOs have historically not physically aggregated the clinical data to which they provide access. Typically, much of the data remains stored locally at participating provider organizations and is retrieved only on demand in the context of a specific patient search. HIOs are now more aggressively pursuing the strategy of physically aggregating and storing patient data within their own data repositories, as this allows them to provide additional data-delivery and analytic services and to differentiate themselves from the data-exchange capabilities that are increasingly built into EHR products. This transition, however, requires HIOs to upgrade their technologies, their data-normalization capabilities, and their governance documents. Also, not all participants in HIOs wish to submit all of their clinical data to an external, centralized repository due to privacy or data-ownership concerns. Hence, it may be time-consuming and/or not always possible for HIOs to fully transition to this model of centralized data storage.

POTENTIAL PATHS FORWARD

- HIOs could develop centralized data repositories for aggregating clinical data submitted by participants. If the HIO's core technology does not support this function, a separate data-repository technology can be procured and integrated with the core technology. This data repository should include a standardized/normalized data model that supports relevant data analytics.
- HIO participants could be incentivized to contribute their data to the centralized repository. Incentives could include free data-normalization services or discounts on subscription fees.
- HIOs should seek to make participants feel as comfortable contributing their data to the centralized repository as possible. Steps may include (a) requiring only a subset of structured clinical data initially, such as encounter dates, primary diagnoses, lab results, prescribed medications, performed procedures, blood pressure, and weight; (b) implementing robust security and access controls on the aggregated data to minimize risk of unauthorized disclosure, as well as performing formal penetration testing on the data repository; and (c) developing specific policies regarding access to data in the repository and formalizing these policies in all participation agreements such that they cannot be changed without each participant's consent.

Normalizing Data in Centralized Models

CHALLENGE

As noted above, HIOs are increasingly seeking to provide additional value by physically aggregating data from their multiple participants in central data repositories. Centralized aggregation allows HIOs to consolidate and deliver relevant data in batch mode to payers, ACOs, and other participants for analysis. It also allows HIOs to, themselves, perform data analytics for risk stratification, chronic disease management, and quality improvement. However, data aggregation, consolidation, and analysis require that heterogeneous clinical data from multiple sources be standardized and normalized, which remains a complex and time-consuming task. For example, lab results from hospitals are often represented using the hospitals' own coding systems, rather than the standardized LOINC coding system, necessitating code mapping and translation when the data are aggregated. Also, the representation and completeness of clinical data transmitted using the C-CDA document standard can still vary considerably depending on the specific hospital or ambulatory provider that generates these data.

POTENTIAL PATHS FORWARD

- Regional HIOs can engage third-party data-cleansing and data-normalization firms, such as Diameter Health, InteropX, and Redox.
- Stakeholders can lobby federal regulators to increase the level of data standardization required of EHR vendors, clinical laboratories, and other contributors of data to HIOs.

Matching Patient Data in Centralized Models

CHALLENGE

Correctly matching data received from different organizations to the appropriate patient remains a major challenge for not just HIOs, but many payers and providers as well. Although the master patient index (MPI) technologies used by HIOs have improved, certain HIOs have reported that wholly reliable patient matching still requires a considerable degree of manual curation, i.e., manual review of potential duplicate records or uncertain match results. In the absence of sufficient manual effort devoted to this task, multiple identities may exist for individual patients within an MPI, which results in fragmentation of these patients' data and incorrect or incomplete results in response to data queries. Such errors undermine clinicians' confidence in the HIO's data and can reduce their use of the HIO. A similar patient-matching problem exists when clinicians access the state's immunization registry and prescription drug-monitoring program (i.e., CURES) database. This problem undermines the value being provided by HIOs that directly interface to these state databases as a convenience for their users.

POTENTIAL PATHS FORWARD

- Outside experts or HIOs themselves could more rigorously study the performance of HIOs' MPI technologies and identify any weaknesses and their root causes.
- Technology vendors, such as Verato, can continue honing their solutions for improving patient-matching performance and consider partnering with regional HIOs as customers.
- State officials who oversee the CAIR2 and CURES databases could more rigorously analyze the patient-matching techniques used and the accuracy of results delivered by their databases. They could identify any weaknesses and work to resolve them in order to improve the match rate and reduce the likelihood of incorrect matches. The state may consider procuring a more advanced matching technology.

Need for Centralized Consent Management

CHALLENGE

Currently, a patient's consent to have her data shared via an HIO is collected and stored separately by each provider organization participating in the HIO. Each participant organization's local interface is configured accordingly, so that only the data of patients who have consented to participate in the HIO are made available in response to requests from other organizations. This model makes it difficult for HIOs to ascertain whether the absence of a patient's data in response to a request is because there are no data for that patient at the responding organization or because the patient has not consented to have her data at that organization shared with the given HIO. This leads to situations, for example, in which a provider knows that a patient has received services at an organization, but retrieves no data on that patient from that organization, leaving uncertainty as to whether the cause is a consent issue or an error in the HIO (for example, a patient-matching error). Such uncertainty can undermine confidence in the HIO's data among provider organizations and reduce their use of the HIO.

POTENTIAL PATHS FORWARD

- Regional HIOs could implement centralized consent-management systems that can be populated by all provider organizations participating in a given HIO and accessed by the HIO's technology at the time that data requests are issued. Such a technology could, for example, enable patients to specify global consent preferences regarding HIO data access across all their health care provider organizations, as well as enable an HIO to cross-reference its MPI to its consent records to identify and contact patients who have not consented to sharing some or all of their data.
- Regulators could also further clarify and align statutes and regulations affecting patient privacy to make centralized consent management simpler. As outlined in the challenge below regarding privacy regulations, the nuances and discrepancies that exist among the state and federal regulations are incredibly complex.

Need for Referral-Management Capabilities for Population-Health Management

CHALLENGE

Most HIOs do not yet provide referral-management and care-management tools. Such applications enable referral requests to be made and consult notes to be delivered via the HIO technology, as well as oversight to be provided for the referral process (e.g., referral authorization, appointment reminders, transportation assistance). Certain commercial vendors offer third-party referral-management solutions, but they require technical integration with the HIO's core technology and may entail the use of separate interfaces or applications by HIO participants.

POTENTIAL PATH FORWARD

HIOs could implement closed-loop referral-management capabilities that are tightly integrated with their core technologies and, if possible, with the EHRs of participating organizations. If the HIO's core technology does not support this function, a separate referral-management technology could be procured and integrated. Available third-party commercial products include ACT.md, Netsmart, and CrossTx.

Need for Robust Real-Time Encounter-Notification Capability

CHALLENGE

Regional HIOs are just beginning to provide real-time event-notification services. However, the necessary real-time HL7 ADT data submissions from all hospitals and referring physicians are generally not yet in place, nor are the mechanisms for stakeholders to subscribe to and receive alerts regarding events of interest. One key challenge in implementing this feature is maintaining an up-to-date mapping between patients and the providers and insurers who are interested in and authorized to receive relevant alerts about them.

POTENTIAL PATH FORWARD

HIOs could develop or procure publish/subscribe mechanisms and patient-attribution data for routing event notifications to appropriate recipients. Third-party commercial vendors such as Audacious Inquiry and Collective Medical Technologies provide such services.

Privacy Regulations Inhibiting Behavioral Health and Nonclinical Data Sharing

CHALLENGE

HIPAA and state regulations impose additional consent requirements for the sharing of mental health and substance-use data by provider organizations. These regulations typically require an affirmative ("opt-in") consent model for these specific types of data, even when the default consent model for an HIO is "opt-out." The likelihood of an HIO obtaining that much more burdensome level of consent from all participants is far lower. This dynamic can result in significant gaps in the mental health and substance-use data available via HIOs. HIPAA also prohibits the sharing of protected health information with organizations that are not "covered entities" in the absence of explicit patient consent. Such organizations include various social service agencies, such as housing agencies, employment agencies, food-assistance agencies, and correctional facilities, whose data are relevant to coordinating "whole person care" to underserved populations.

POTENTIAL PATHS FORWARD

- To address restrictions on the sharing of mental health and substance-use data, HIOs and the participating provider organizations that serve patients with those needs could collaborate to better streamline the process of consenting patients specifically to share these types of data. Streamlining would primarily require workflow and policy changes at those provider organizations but could also involve HIOs implementing centralized consent-management systems (see above).
- To address the HIPAA proscriptions on the sharing of PHI with noncovered entities, HIOs could explore the creation of business-associate agreements (BAAs) with social service agencies, which may allow data sharing without explicit patient consent. Given that provider organizations already have BAAs in place with their HIOs, this approach may require also modifying those BAAs. Stakeholders may also consider lobbying federal regulators for additional clarity on these legal complexities.

Notes: *API* is application programming interface; *CAIR2* is California Immunization Registry; *C-CDA* is Consolidated-Clinical Document Architecture; *CURES* is Controlled Substance Utilization Review and Evaluation System; *HIMSS* is Healthcare Information and Management Systems Society; *HIPAA* is Health Information Portability and Accountability Act; *HL7* is Health Level Seven International; *LOINC* is Logical Observation Identifiers Names and Codes; *PHI* is protected health information.

Types of Entities That May Participate in Regional HIOs

Nearly every type of health care entity, no matter how small or how specialized, could improve the care it offers patients by participating in data exchange. However, due to a host of business, financial, and technological reasons, not every entity is equally likely to participate in its regional HIO. Each entity will weigh the benefits of participating against the costs of doing so. It will also examine the types of data its regional HIO offers and expects members to contribute — and whether those data align with the entity's needs and capabilities. Ultimately, all of these factors amount to a question of value: Compared to other data-exchange solutions available to a given entity, does its regional HIO meet enough unique needs to justify the cost and effort required to join?

Table 3. HIO Participation Considerations for Various Health Care Entities

PARTICIPATION		DATA THE ENTITY MAY...	
Reasons to participate	Barriers to participation	Contribute to the HIO	Seek from the HIO
HIGH LIKELIHOOD OF PARTICIPATION			
Private Hospitals			
► Exchange clinical information with ambulatory centers as part of referral network ► Participation in risk-bearing or pay-for-performance contracts that require data exchange for care coordination ► Especially high use among EDs and outpatient clinics within hospitals	► Most use major EHR platforms with built-in HIE capabilities via the national HIE networks. ► The value of receiving data from ambulatory centers has been limited, especially when the number of ambulatory participants in the HIO is low.	► Inpatient and ED admissions (ADT) ► Lab, radiology, and other results (HL7) ► Structured encounter summary documents (C-CDA) ► Unstructured summary documents (e.g., discharge summary)	► Clinical data contributed by other hospitals ► Outpatient encounter notifications (ADT) ► Outpatient lab, radiology, and other results
Public Hospitals			
► Participation in risk-bearing or pay-for-performance contracts that require data exchange for care coordination ► Less likely to benefit from the private HIO resources available to hospitals in larger systems	► Costs associated with both up-front IT integration work and ongoing subscription and maintenance fees ► The value of receiving data from ambulatory centers has been limited, especially when the number of ambulatory participants in the HIO is low.	► Same as private hospitals	► Same as private hospitals
Large Outpatient Providers (multispecialty, community health centers, IPAs)			
► Participation in risk-bearing or pay-for-performance contracts that require data exchange for care coordination and population health ► Especially need ED or inpatient information from hospitals, including encounter notifications and discharge summaries	► Costs associated with both up-front IT integration work and ongoing subscription and maintenance fees ► Alternatives for data exchange through participation in private HIOs (e.g., in IDNs, IPAs, or ACOs) ► Lack of integration with the providers' EHRs may make access to HIO data cumbersome and time-consuming.	► Outpatient encounter notifications (ADT) ► Outpatient lab, radiology, and other results (HL7) ► Medication lists and medication allergies ► Immunizations and reportable diseases ► Structured encounter summary documents (C-CDA) ► Unstructured summary documents (specialty consult notes)	► Notifications of hospital and ED encounters ► Result data from hospitals, other outpatient providers, and lab/imaging centers ► Outpatient medication lists ► Structured and unstructured summary documents from hospitals, EDs, and outpatient providers ► Immunization registry records

Table 3. HIO Participation Considerations for Various Health Care Entities, *continued*

PARTICIPATION		DATA THE ENTITY MAY…	
Reasons to participate	Barriers to participation	Contribute to the HIO	Seek from the HIO
MEDIUM LIKELIHOOD OF PARTICIPATION			
Laboratory and Imaging Centers			
➤ Provides a single interface hub for delivering results to many providers ➤ Aggregates and delivers results to disease registries, population-health programs, etc.	➤ Costs associated with both up-front IT integration work and ongoing subscription and maintenance fees ➤ Existing alternative channels to deliver results to ordering providers (via dedicated HL7 interfaces)	➤ Lab results and radiology reports ➤ Radiology images	➤ Lab and radiology orders
Payers (including county, state, and commercial plans)			
➤ Contribute claims data to supplement missing clinical data due to incomplete participation by provider organizations ➤ Access clinical data to facilitate population-health, care-coordination, quality, and pay-for-performance initiatives	➤ Subscription fees charged by HIOs ➤ Data sharing agreements can sometimes restrict payer access to clinical data, reducing the value of participation. ➤ Reluctance to share claims data or membership data with competitors	➤ Claims data ➤ Membership and PCP-assignment data	➤ Real-time notification of hospital, ED, and outpatient encounters ➤ Structured clinical data to drive population-health and quality-measurement activities
Small FQHCs, Community Health Clinics, and Small Physician Practices			
➤ Participation in risk-bearing or pay-for-performance contracts that require data exchange for care coordination ➤ More likely to use less expensive EHRs that do not yet include access to other vendor-centric HIE networks ➤ Less likely to be participating in a private HIO through an IDN, IPA, or ACO	➤ Costs associated with both up-front IT integration work and ongoing subscription and maintenance fees ➤ Lack of integration with the providers' EHRs may make access to HIO data cumbersome and time-consuming.	➤ Same as large outpatient providers, although often limited because of costs and difficulties of EHR integration	➤ Same as large outpatient providers
EMS Providers			
➤ Facilitate clinical care during patient treatment and transport ➤ Prepare receiving ED for patient arrival ➤ Track patient outcomes subsequent to transport	➤ Limited resources for technical integration of EMS information systems with HIO ➤ Limited business drivers for EMS integration with HIOs	➤ Clinical status during transport to ED, including chief complaint, vital signs, and acuity	➤ Medication lists ➤ Medication allergies ➤ Problem lists ➤ POLST/DNR forms

Table 3. HIO Participation Considerations for Various Health Care Entities, *continued*

PARTICIPATION		DATA THE ENTITY MAY…	
Reasons to participate	Barriers to participation	Contribute to the HIO	Seek from the HIO
LOW LIKELIHOOD OF PARTICIPATION			
Urgent Care Centers			
▶ Facilitate diagnosis and treatment ▶ Assist in arranging appropriate follow-up care ▶ Facilitate referrals to affiliated provider organizations ▶ Participation in risk-bearing or pay-for-performance contracts that require data exchange for care coordination	▶ Costs associated with both up-front IT integration work and ongoing subscription and maintenance fees ▶ Urgent care centers unaffiliated with IDNs or ACOs may have little financial incentive to join an HIO.	▶ Outpatient encounter notifications (ADT) ▶ Lab results and radiology reports for locally performed studies ▶ Structured encounter summary documents (C-CDA) ▶ Unstructured discharge summaries	▶ Problem lists ▶ Medication lists ▶ Medication allergies ▶ Past lab results and radiology images ▶ Record of past inpatient and outpatient encounters, including specialists
Long-Term Care (LTC) and Skilled Nursing Facilities (SNFs)			
▶ Participation in risk-bearing or pay-for-performance contracts that require data exchange for care coordination and avoidance of readmissions ▶ Especially need ED or hospital discharge information for returning or incoming residents ▶ Need to transmit patient data to hospitals for patient transfers to the ED or inpatient wards, to prevent readmissions, facilitate clinical care, and reduce length of stay	▶ Some do not yet have sophisticated EHRs that can interface with an HIO. ▶ The EHRs that are used are different from those used by hospitals and outpatient providers, and are not likely to have the interoperability features required under the meaningful use EHR certification program. ▶ Initial funding provided under HITECH to assist HIO onboarding did not include LTC facilities and SNFs.	▶ Medication lists ▶ Problem lists ▶ Progress notes ▶ Lab results and radiology reports	▶ Structured and unstructured transition of care documents from hospitals and EDs
Social Service Agencies			
▶ Enable county-driven initiatives started through federal waiver programs, such as Whole Person Care Pilots or Health Homes, or other local service providers to coordinate social services with medical services	▶ Social service agencies are not covered entities under HIPAA regulations, so information sharing from medical providers requires explicit ("opt-in") patient consent.	▶ Various social determinants of health, including employment, housing, and food-security status	▶ Mental and physical health problems ▶ Treatment and appointment schedules (for transport assistance) ▶ Medi-Cal status and PCP assignment
Inpatient Mental Health and Substance-Use Treatment Facilities			
▶ Exchange clinical information about shared patients	▶ Stringent and complex restrictions on sharing of data related to mental health and substance use constrain ability to contribute data.	▶ Typically limited because mental health data are subject to additional state and federal restrictions on sharing, and substance-use treatment facilities must obtain explicit patient consent for any data sharing	▶ Medication lists ▶ Problem lists

Notes: *C-CDA* is consolidated-clinical document architecture; *DNR* is do not resuscitate; *EMS* is emergency medical services; *FQHC* is Federally Qualified Health Center; *HIPAA* is Health Information Portability and Accountability Act; *HL7* is Health Level Seven International; *PCP* is primary care provider.

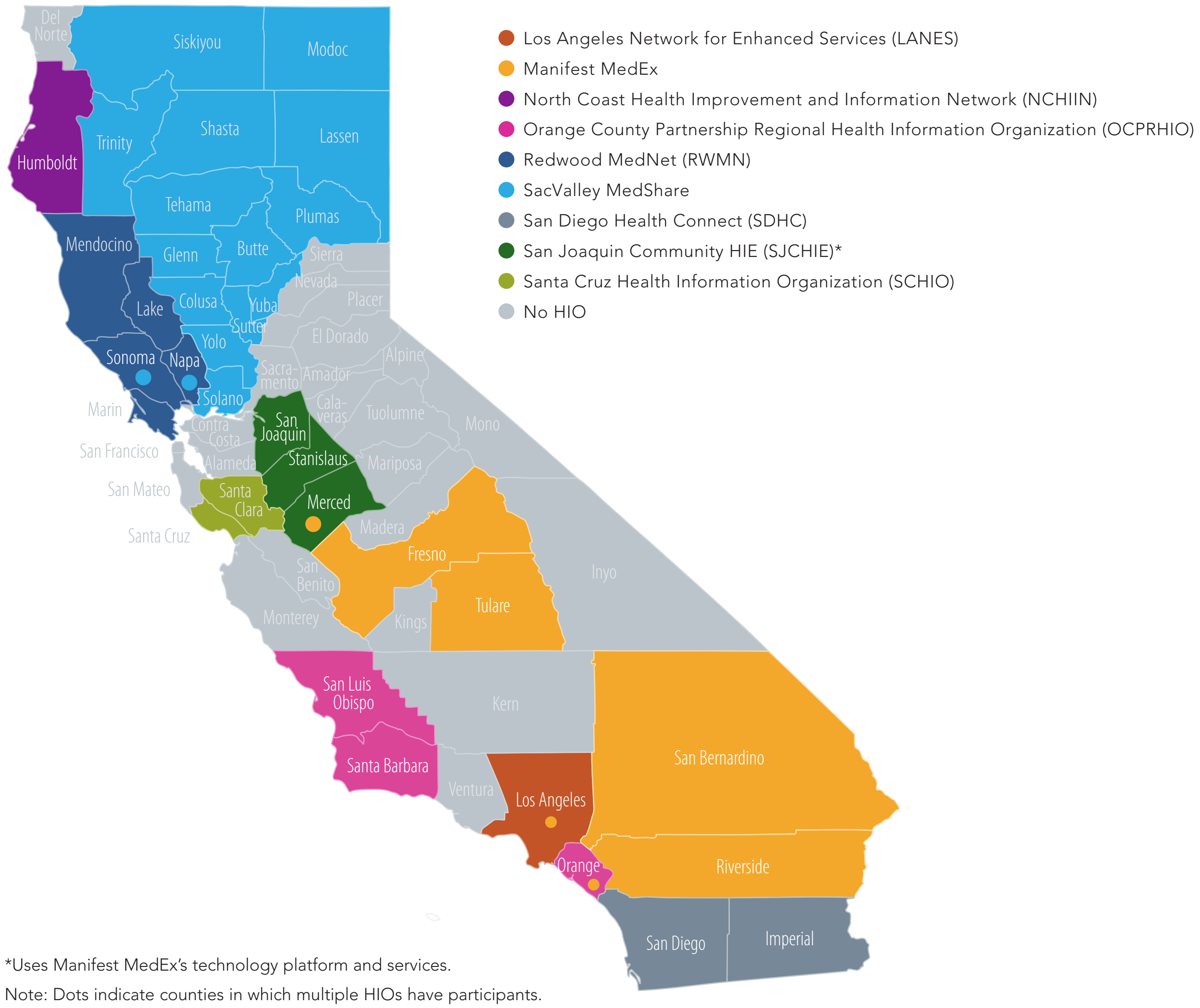
Snapshot of Nine California Regional HIOs

Federal funding provided by the HITECH Act, passed in 2009, spurred substantial growth in the number of both public and private HIOs in California. With minimal state-level coordination or regulation of this burgenoning new patchwork of HIE organizations, its growth unfolded both organically and unevenly. On the one hand, that organic growth has allowed regional dynamics to shape solutions truly tailored to local needs. On the other hand, some regions and entities have been left behind or left vulnerable to changing market forces.

California's regional HIOs touch 35 of 58 counties statewide and about 22 million lives. An estimated 187 hospitals statewide participate in these initiatives, but close to 200 hospitals do not. Many other types of providers, ranging from skilled nursing facilities to laboratories, have far lower participation rates (see Table 3 above).

What follows are high-level snapshots of nine major regional HIOs in California, including the areas they serve, the types of data exchange they facilitate, the services they provide, the members they serve, and some of the historical and geographic context that has led them to evolve in the unique ways that they have. (This information is valid as of Q2 2018.)

Figure 1. Nine Regional HIOs Operating in California



*Uses Manifest MedEx's technology platform and services.

Note: Dots indicate counties in which multiple HIOs have participants.

Los Angeles Network for Enhanced Services (LANES)

Participants

Total participants: ~50

- Hospitals: 4 county, 8 private
- Clinics: 24 county, 5 to 10 community
- County behavioral health

Services

- Longitudinal patient record, with web-portal viewer
- Real-time event-notification services
- Direct secure messaging
- Analytics reports (population health, pay-for-performance metrics)

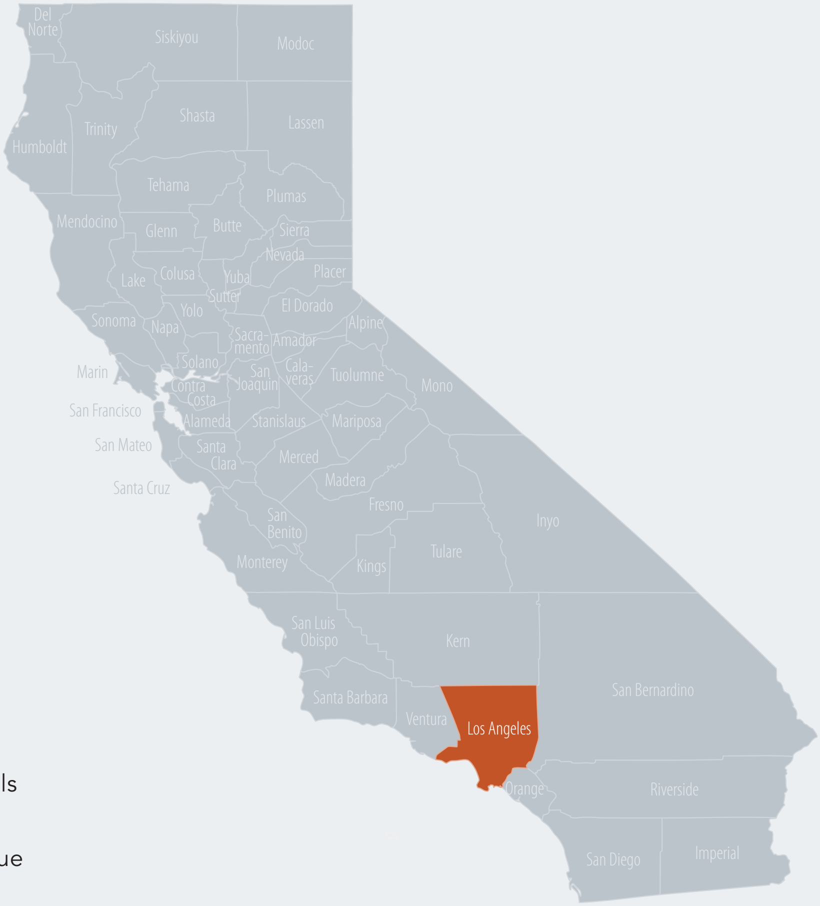
Types of Data

- Lab results
- Medication lists
- Clinical notes

Pricing

Subscription fees from participating hospitals and health plans

- *Hospitals*: Fixed fees, based on net revenue ($25K to $125K/year)
- *Health plans*: $1 PMPY fee
- *IPAs*: Connection and subscription fees (fee structure not available)
- *FQHCs*: Connection and subscription fees subsidized for 2 years (fee structure thereafter not available)



About LANES

LANES is seeking to reestablish itself after several years of dormancy as a regional HIO for all provider organizations and payers in LA County. Due to the predominance of past and present funding by LA County, LANES is fighting the misperception that it is an HIO primarily for safety-net providers (i.e., county medical facilities, FQHCs, and LA Care). In fact, LANES is striving to connect all care delivery providers in Los Angeles, including primary care providers, specialists, hospitals, health plans, and long-term care facilities. LANES physically aggregates data in a central data repository, which positions it well to serve customers seeking population-health analytics, bulk data feeds to payers and ACOs, and other data-dependent services.

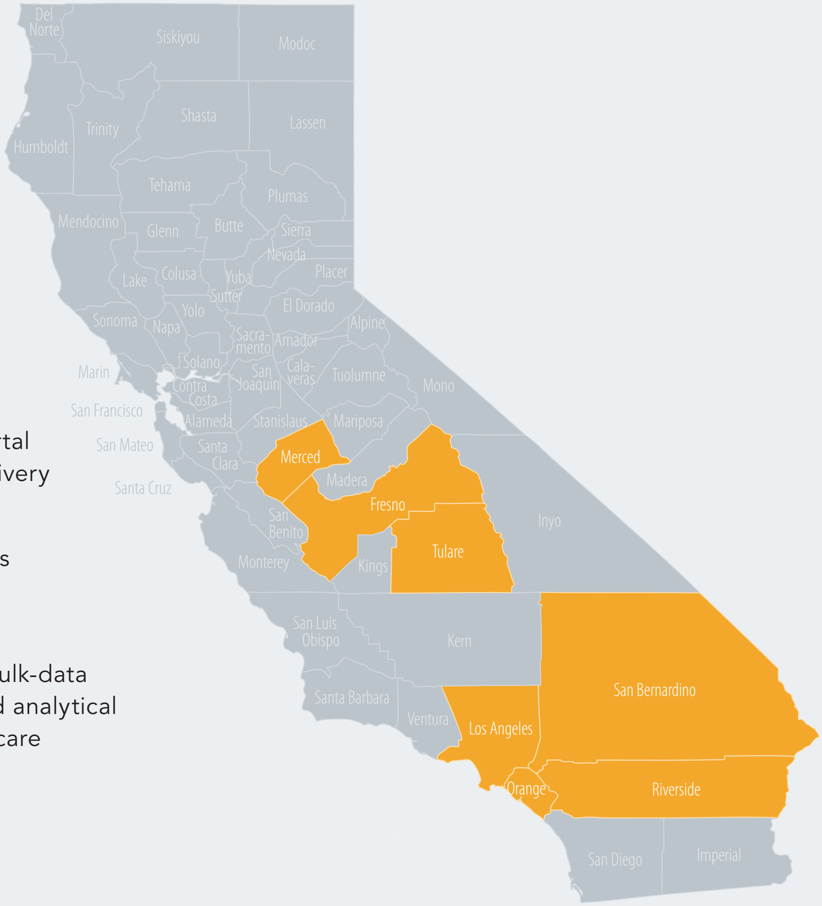
Notes: *ACO* is accountable care organization; *FQHC* is Federally Qualified Health Center; *HIO* is health information [exchange] organization; *IPA* is independent physician association; *PMPY* is per member per year.

Manifest MedEx

Participants

Total participants: 243

- 65 hospitals
- 58 IPAs or medical groups
- 54 community clinics
- 49 small practices
- 17 others (ACOs, health plans, county agencies)



Services

CURRENT

- Longitudinal patient record, with web-portal viewer and EHR-integrated document delivery
- Real-time event-notification services
- Data submission to public health registries (immunizations and reportable events)

FUTURE

- Data aggregation and normalization for bulk-data distribution, real-time access via APIs, and analytical services in support of population health, care coordination, etc.

Types of Data

- ADT feeds
- Medication lists
- Lab results
- Immunization records
- Claims data
- C-CDA documents via the eHealth Exchange network

Pricing

- *Hospitals*: A sliding-scale annual subscription fee ranging from $10K to $100K (based on hospital's net patient revenue) plus a $35K flat implementation fee
- *Ambulatory providers*: No annual subscription or implementation fees

About Manifest MedEx

Manifest MedEx has a uniquely large footprint in the state of California. Manifest MedEx operates the technical infrastructure for three other HIOs (Central Valley HIE, San Joaquin Community HIE, and Inland Empire HIO), each of which handles its own local recruitment, training, and other on-the-ground support. Manifest MedEx also boasts substantial participation by health plans, including commercial payers — Blue Shield is a particularly strong participant — and Medi-Cal managed care plans (Inland Empire Health Plan, Health Plan of San Joaquin).

Notes: *ACO* is accountable care organization; *ADT* is admission, discharge, and transfer; *API* is application program interface; *C-CDA* is consolidated-clinical document architecture; *EHR* is electronic health record; *HIE* is health information exchange; *HIO* is health information [exchange] organization; *IPA* is independent physician association.

North Coast Health Improvement and Information Network (NCHIIN)

Participants

Total participants: >9

- 4 hospitals
- 1 health plan
- 2 labs
- 90% of PCPs in Humboldt County
- County agencies (Public Health Branch, Mental Health Services)

Services

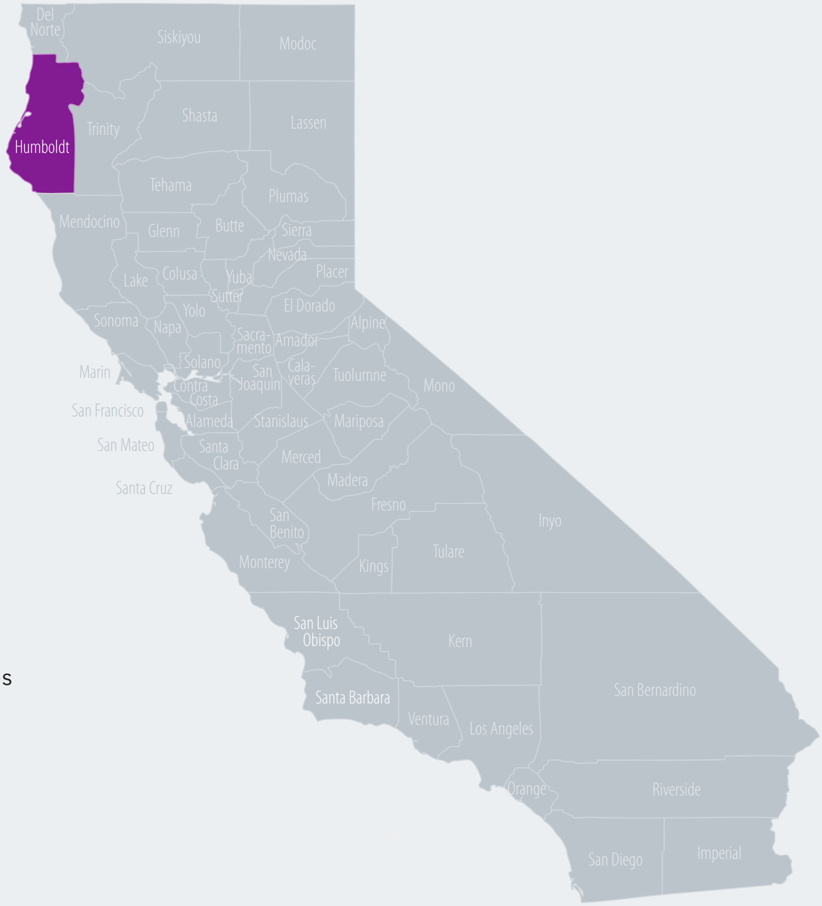
- Patient data summaries (faxed to hospital EDs when patients seek care there)
- Patient mental health summaries
- Real-time event-notification services
- Results and document delivery
- Care-management platform
- Data submission to public health registries (CalREDIE and CAIR2)

Types of Data

- Lab results
- Clinical notes
- ADT feeds
- Immunization records
- Demographic data
- Health plan eligibility
- Contact information for case managers
- Contact information for probation officers
- Jail entry and release data (name and dates)

Pricing

- $35/user/month
- Fee charged to hospitals and labs for each result delivered (28,000 results delivered per month)

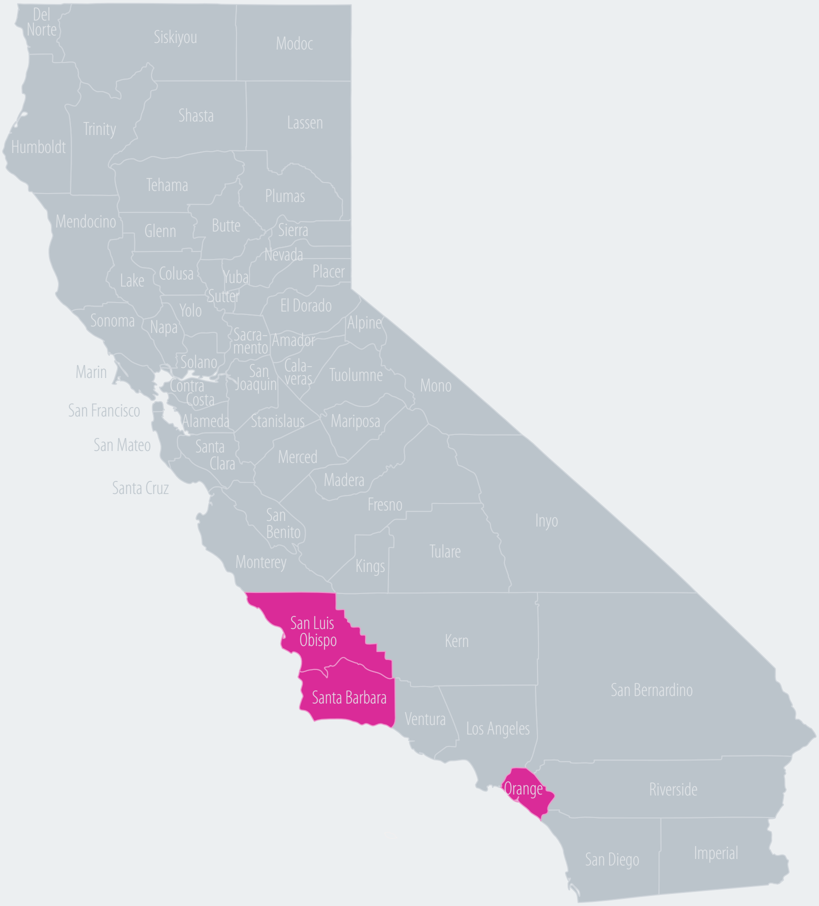


About NCHIIN

North Coast Health Improvement and Information Network has one of the smallest budgets of any regional HIO in the state and is highly focused on supporting a "social model" of health care, which depends on the integration of medical services and nonmedical social services. As a result, NCHIIN has significant experience in sharing patient data between medical providers and social service agencies, including navigating complex HIPAA and state regulatory challenges. NCHIIN is also very focused on supporting and integrating care-coordination capabilities. NCHIIN has significant mission and operational staffing overlap with the Humboldt IPA.

Notes: *ADT* is admission, discharge, and transfer; *CAIR2* is California Immunization Registry; *CalREDIE* is California Reportable Disease Information Exchange; ED is emergency department; *HIO* is health information [exchange] organization; *HIPAA* is Health Insurance Portability and Accountability Act; *IPA* is independent physician association; *PCP* is primary care provider.

Orange County Partnership Regional Health Information Organization (OCPRHIO)



Participants

Total participants: >20

- 17 hospitals (out of 20)
- 3 large IPAs or medical groups
- 30 clinics (some using secure messaging only)

Services

- Longitudinal patient record, with web-portal viewer and EHR-integrated viewers
- Results and document delivery (lab, radiology, pathology)
- Direct secure messaging

Types of Data

- ADT feeds
- Lab results
- Radiology reports
- Pathology results
- C-CDA documents
- Radiology images

Pricing

- Hospitals: ~$50,000/year
- Medical groups: Variable, depending on number of interfaces (starts at ~$7,500/year)
- Sites using web-portal viewer only: $40/physician/year

About OCPRHIO

A significant proportion of the patient population served by OCPRHIO lives in or receives medical care in adjoining counties (LA, Riverside, San Bernardino, and San Diego). OCPRHIO members therefore highly prioritize its ability to exchange data with HIOs in neighboring counties. Many of OCPRHIO's participating community clinics and small physician practices do not yet have data interfaces, and are accessing HIO data exclusively via a web-portal viewer.

Notes: *ADT* is admission, discharge, and transfer; *C-CDA* is consolidated-clinical document architecture; *EHR* is electronic health record; *HIO* is health information [exchange] organization; *IPA* is independent physician association.

Redwood MedNet (RWMN)

Participants

Total participants: >8

- 6 hospitals
- 600 outpatient providers (IPA and medical groups, community clinics)
- County behavioral health

Services

CURRENT

- Results and document delivery (lab, radiology)

FUTURE

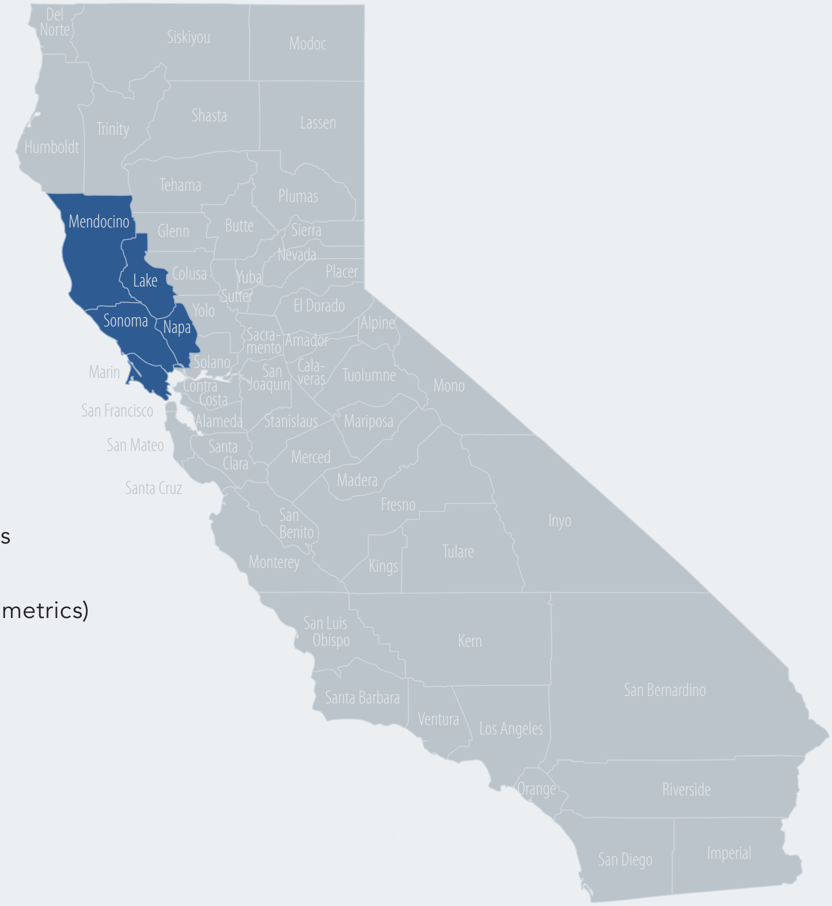
- Longitudinal patient record, with web-portal viewer and EHR-integrated viewers
- Analytics reports (population health, pay-for-performance metrics)
- Access to social determinants of health

Types of Data

- ADT feeds
- Lab results
- Radiology reports
- Health plan eligibility

Pricing

Details unavailable



About RWMN

Redwood MedNet, which is built on open-source software with cloud-hosted infrastructure, has a narrower focus than other regional HIOs. Rather than aiming to support general patient-data exchange, RWMN focuses on facilitating HL7 result delivery and supporting targeted projects to improve the coordination of care for the local safety-net population. RWMN has relied heavily on one-off development projects as a revenue source and is now focused on growing its recurring subscription revenue in order to strengthen its financial sustainability.

Notes: *ADT* is admission, discharge, and transfer; *EHR* is electronic health record; *HIO* is health information [exchange] organization; *HL7* is Health Level Seven International; *IPA* is independent physician association.

SacValley MedShare

Participants

Total participants: 30

- 15 hospitals
- 24 clinics
- 1 health plan
- 2 imaging centers

Services

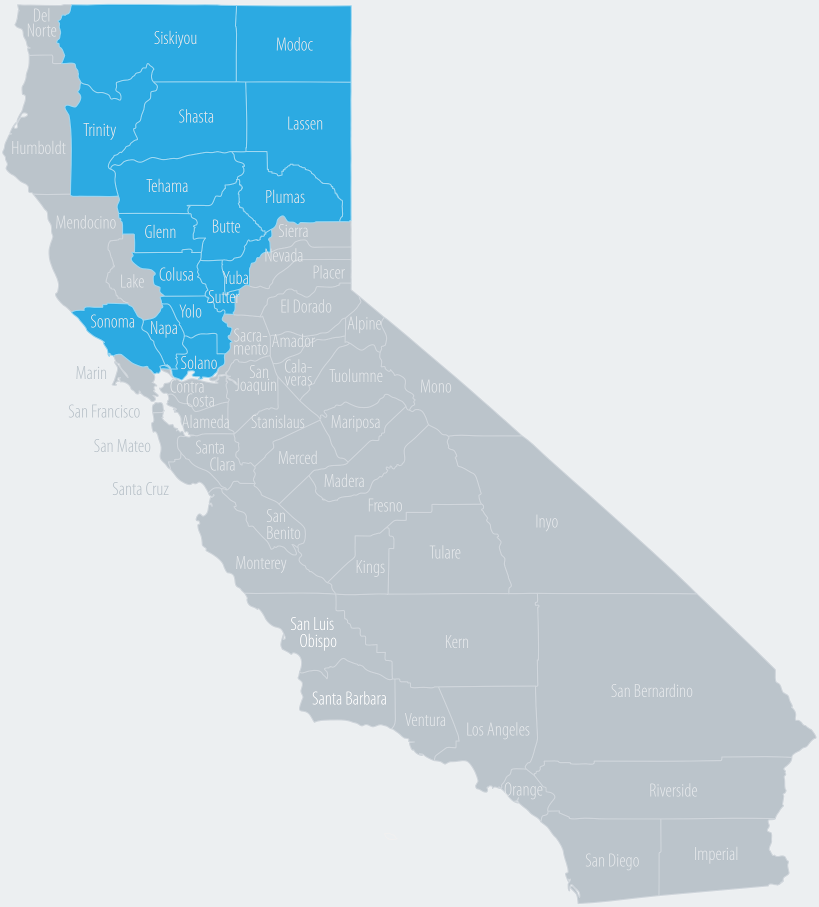
- Longitudinal patient record, with web-portal viewer and EHR-integrated viewers
- Real-time event-notification services
- Access to national health information exchange networks (eHealth Exchange)

Types of Data

- ADT feeds
- Lab results
- Radiology reports
- Medication lists
- Clinical notes
- C-CDA documents

Pricing

- Hospitals: Based on number of beds
- Clinics and practices: Based on number of FTE MDs and DOs
- Imaging centers: Based on number of radiologists reading image
- Health plans: Based on number of covered lives

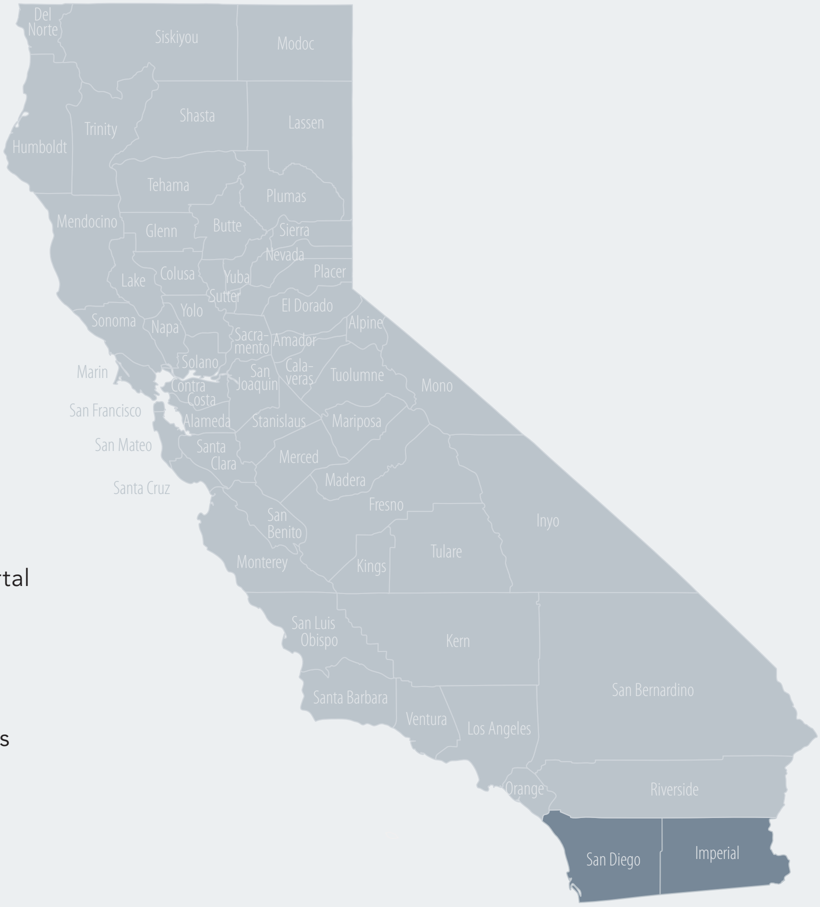


About SacValley MedShare

SacValley MedShare is the only regional HIO operating in many of California's rural counties. It faces a unique consent-management challenge because its patients are sometimes referred to providers in Nevada, which has a statewide "opt-in" consent policy — in contrast to the HIO, which has a default "opt-out" policy for California providers. SacValley is in the process of integrating with a Medi-Cal managed care plan that has members in roughly half of the counties of this region, and has actively supported HIE as a means to improve the quality and control the costs of the care it provides.

Notes: *ADT* is admission, discharge, and transfer; *C-CDA* is consolidated-clinical document architecture; *DO* is doctor of osteopathic medicine; *EHR* is electronic health record; *FTE* is full-time equivalent; *HIO* is health information [exchange] organization; *MD* is medical doctor.

San Diego Health Connect (SDHC)



Participants

Total participants: 40

- 21 hospitals
- 1 IPA
- 17 community clinics
- 1 ambulance company

Partial participants
(secure messaging only):

- 2 counties
- 80 SNFs
- 5 hospices
- 28 ambulatory sites

Services

- Longitudinal patient record, with web-portal viewer and EHR-integrated viewers
- Results and document delivery (lab)
- Real-time event-notification services
- Data submission to public health registries
- Prehospital EMS reporting
- Secure messaging

Types of Data

- C-CDA documents
- HL7 v2 messages
- Radiologic and cardiologic images
- POLST documents
- NEMSIS electronic patient care reports

Pricing

Details unavailable

About SDHC

San Diego Health Connect was founded and initially operated largely through generous funding from a federal government grant. In 2013, when those grant funds ran out, the HIO sought and began receiving most of its funding from the county government and the large health systems operating in the county. The HIO is now under pressure to demonstrate tangible value, particularly as alternative HIE resources provided directly by providers' EHR products gain more capabilities and wider reach throughout the county. One of SDHC's most high-value opportunities is providing hospital and ED encounter-notification services, given the broad participation of regional hospitals in its network. One challenge of note for SDHC is the heterogeneity of consent policies among its participants. Some still use an opt-in consent policy, which sometimes results in the appearance that patient data are missing from these participants.

Notes: *C-CDA* is consolidated-clinical document architecture; *ED* is emergency department; *EHR* is electronic health record; *EMS* is emergency medical services; *HIE* is health information exchange; *HIO* is health information [exchange] organization; *HL7* is Health Level Seven International; *IPA* is independent physician association; *NEMSIS* is National Emergency Medical Services Information System; *POLST* is Physician Orders for Life-Sustaining Treatment; *SNF* is skilled nursing facility.

San Joaquin Community HIE (SJCHIE)

Participants

Total participants: 6

- 1 hospital
- 3 clinics
- 2 health plans

Services

CURRENT

- Longitudinal patient record, with web-portal viewer
- Real-time event-notification services
- Care-management platform*

FUTURE

Data aggregation and normalization for:

- Bulk-data distribution
- Real-time access via APIs
- Analytical services in support of population health, care coordination

Types of Data

- ADT feeds
- Lab results
- Immunization records
- C-CDA documents
- Medication lists

Pricing

Details unavailable

About SJCHIE

Through a unique partnership, Manifest Medex provides the technical infrastructure underlying the San Joaquin Community HIE, while the HIE provides the local recruiting, consulting, and operational support services. Members have access to data from other regional HIOs that have similar "affiliate" relationships with Manifest Medex. SJCHIE is leveraging its data exchange and analytics and reporting features to actively support San Joaquin County's Whole Person Care Pilot initiative. SJCHIE is also in the process of contracting with a care-management vendor to integrate with the Manifest Medex technology.

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*Data exchange platform served by Manifest Medex. Community engagement and care-management platform offered specifically by SJCHIE.

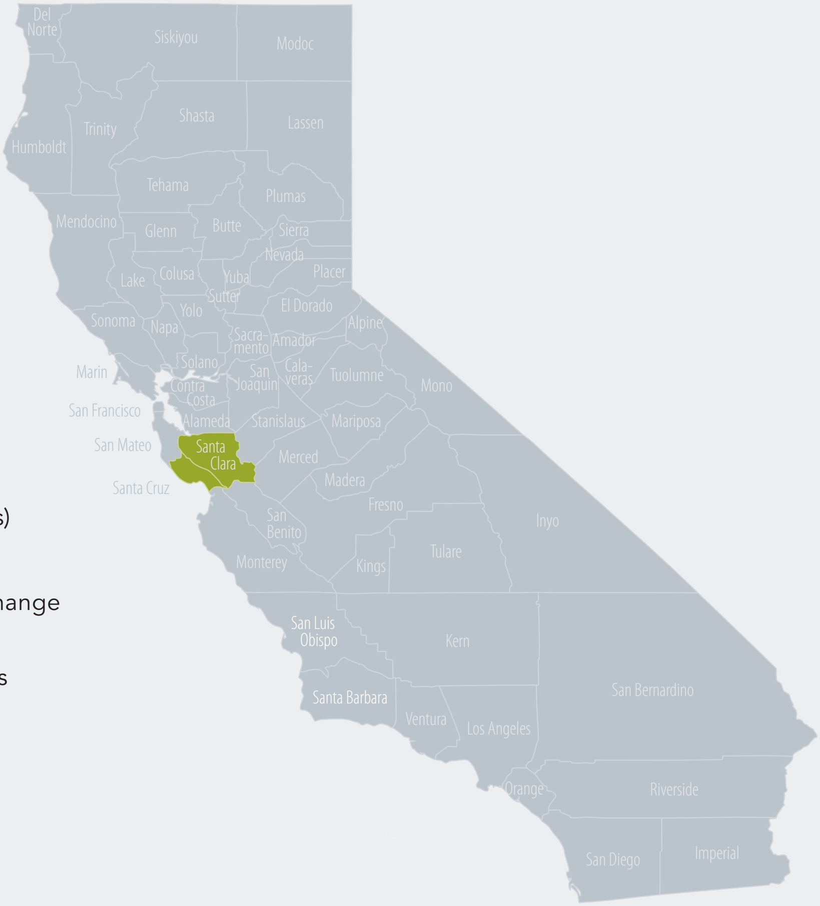
Notes: *ADT* is admission, discharge, and transfer; *API* is application program interface; *C-CDA* is consolidated-clinical document architecture; *HIE* is health information exchange; *HIO* is health information [exchange] organization. SJCHIE uses Manifest Medex's technology platform and services.

Santa Cruz Health Information Organization (SCHIO)

Participants

Total participants: 46

- 7 hospitals
- 12 clinics
- 2 IPAs or large medical groups
- 12 small practices
- 11 labs or imaging centers
- 2 health plans



Services

- Longitudinal patient record, with web-portal viewer and EHR-integrated viewers
- Results and document delivery (lab, radiology, transcribed notes, C-CDAs)
- Real-time event-notification services
- Access to national health information exchange networks (Carequality, eHealth Exchange)
- Data submission to public health registries (CalREDIE and CAIR2)
- Analytics reports (population health, pay-for-performance)
- Referral management
- Communication with nonmedical service organizations

Types of Data

- ADT feeds
- Lab results
- Radiology reports
- Clinical notes
- C-CDA documents

Pricing

Details unavailable

About SCHIO

Formed in 1995, Santa Cruz HIO is California's oldest regional HIO, and it has, over those 20+ years, built significant momentum and traction within the community. It serves a county that is small and lightly populated compared with most other population centers that have a regional HIO. Nonetheless, it has become financially stable and self-sustaining. SCHIO has substantial participation from both the local county's safety-net providers and its Medi-Cal managed care plan.

Notes: *ADT* is admission, discharge, and transfer; *API* is application program interface; *CAIR2* is California Immunization Registry; *CalREDIE* is California Reportable Disease Information Exchange; *C-CDA* is consolidated-clinical document architecture; *EHR* is electronic health record; *HIO* is health information [exchange] organization; *IPA* is independent physician association. SCHIO is located primarily in Santa Cruz County with locations at Stanford, Palo Alto Medical Foundation (PAMF), and small practices in Santa Clara County.

How Regional Market Dynamics Shape the Role of Regional HIOs

Key Factors

A regional HIO is generally only one of many health care players operating in a given local market. Each player has a unique set of clinical and financial obligations and incentives, and of course, not all of the players are equal. They can differ in any number of ways, including market share, profitability, and customer segment. The one thing they all share is that they are operating within the same region, which includes a unique history, geography, and demographics. With so many stakeholders and forces at play, it can be hard to trace the path of how a particular market's health care ecosystem has evolved. When it comes to the evolution and success of regional HIOs, however, four particular market dynamics seem to be especially influential:

1. **Degree of consolidation and competition** among provider organizations in the region: Larger, more consolidated provider organizations seek to and can provide a broader range of health care services, which incentivizes them to create private HIO infrastructures to streamline cross-disciplinary care, to attract and retain patients within their enterprises with the convenience of a single longitudinal health record, and to support business analytics. If a region is dominated by one or more such entities, they may be fiercely competitive and less inclined to share patient data via a regional HIO, as such sharing may blunt the competitive advantages of their achieved scale.

2. **Heterogeneity of EHR systems** in use among provider organizations: If an EHR vendor achieves substantial market share among the provider organizations in a region and that vendor provides its own proprietary mechanism for data sharing across its customers, then there is less need for a regional HIO. Conversely, regions with fragmented EHR markets depend more on a third party, such as a regional HIO, to organize and enable data sharing across provider organizations.

3. **Presence of a supportive dominant health insurer** that believes in the value of the HIO for purposes of improving care coordination and population health for its members: A dominant health insurer has the business incentive to invest in the regional HIO, as the financial benefits of improved population health and reduced health care utilization within the region accrue largely to itself. In regions with highly fragmented payer markets, it is more difficult for individual insurers to calculate the benefits and justify the costs of their investments in a regional HIO.

4. **Capabilities of the available regional HIO** to provide data-exchange services needed by a significant number of provider organizations and payers in the region and not otherwise provided through their EHR vendors: The more interoperability services that a regional HIO can effectively provide and the better organized and operated the HIO is, the more likely provider organizations will be to benefit from and support its services. As the base of participating provider organizations increases due to this perception of competence, the services of the regional HIO will become that much more valuable, further perpetuating participation and support. The converse dynamic is equally true.

Case Studies: Real-World Implications of Regional Market Dynamics on HIO Strength

Northern Central Valley (north of Sacramento to Oregon border)

Rural, unconsolidated market with a small but well-supported regional HIO

This geographically sizable region* of the state is largely rural and home to only 1.7 million residents. Although it includes some hospitals and outpatient clinics from large, multihospital systems, such as Dignity Health, most of the provider organizations in the region remain independent, including a host of critical access hospitals, community clinic networks, and small, independent practices and medical groups. There is no academic medical center in the region, although the UC Davis Medical Center in the adjoining Sacramento County is a referral hub.

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*This region corresponds roughly to the region served by the SacValley MedShare HIO (profiled on page 23).

The region's spread-out geography and lack of intense competition among provider organizations for the same patient populations limit the degree of resistance on their parts to exchanging data.

Partnership HealthPlan of California (PHC) is a Medi-Cal managed care plan that has members in roughly half of the counties of this region and has actively supported HIE to improve the quality and control the costs of care for this population. PHC is currently integrating with the local regional HIO, SacValley MedShare. This HIO provides a longitudinal medical record and event-notification services based on data from 15 hospitals, 24 clinics, and 2 imaging centers, to date. Although this remains a minority of the provider organizations and payers in the region, the HIO is in active negotiations with other organizations. The overall budget of the HIO and, as a result, its subscription fees for any individual participant are relatively low, helping the HIO to maintain stable operations.

San Francisco Bay Area

Highly consolidated and competitive market with no regional HIO

Despite being home to 7 million residents, the nine-county Bay Area has no regional HIO in operation. The area is dominated by a few large hospital systems, such as Kaiser Permanente, Sutter Health, and Dignity Health, as well as two large integrated delivery networks anchored at academic medical centers (Stanford and UCSF). Outpatient care is also consolidated, with Kaiser Permanente operating about a dozen facilities, the Palo Alto Medical Foundation (also affiliated with Sutter Health) having 15 sites and 900 physicians, the Santa Clara County IPA having over 800 physicians, and Brown & Toland Physicians offering a network of more than 2,500 physicians across 38 Bay Area cities. All of these consolidated organizations are also highly competitive with each other, and each is trying to achieve greater consolidation and clinical integration unto themselves. This likely impedes a willingness to openly cooperate and freely share patient data among themselves.

Health information exchange does occur across the major provider organizations in the Bay Area, but it is enabled by capabilities made available through EHR vendors, such as Carequality, CommonWell Health Alliance, and Epic Care Everywhere, and connectivity among certain of the private HIOs operated by these provider organizations.

San Diego County

Consolidated market with a regional HIO facing stiff competition from EHRs and other alternatives

San Diego County is a relatively densely populated and affluent region, with over 3 million residents. Although its payer market is fragmented, its health care systems, including Sharp HealthCare, Scripps Health, Kaiser Permanente, Palomar Health, and the UC San Diego Medical Center, are highly consolidated. These systems use a small number of EHR systems, predominantly Epic and Cerner, which provide certain native data-exchange capabilities (such as Epic Care Everywhere and connectivity with the Carequality and CommonWell Health Alliance networks). Certain of these health care systems also use additional private HIE technologies.

As the EHR systems and other private HIE technologies used by these health care systems gain increasing capabilities and reach throughout the county, the local regional HIO, San Diego Health Connect, is facing heightened pressure to deliver unique value. The intense competition among those larger health systems may make it challenging for the HIO to encourage the types of data sharing needed to demonstrate additional value, such as contribution of providers' data into a central data repository. The regional HIO does, however, enjoy support and funding from the local government, which is active in providing and coordinating care for the safety-net populations treated by several sizable community health centers and other providers.

Looking Ahead: Policy and Technology Trends to Watch

The larger health care market within which regional HIOs operate is incredibly dynamic. While many policy and technology trends have the potential to shape the fate of HIOs, the following ones loom especially large.

New HITECH Funds on the Horizon for California's Regional HIOs

The California Department of Health Care Services (DHCS) is applying to the Centers for Medicare & Medicaid Services (CMS) for $45 million in federal HITECH Act funds, matched by $5 million in general state funds to onboard more hospital systems and ambulatory providers into regional HIOs. Specifically, the funding will subsidize one-time implementation costs for providers to connect to qualified regional HIOs. Up-front onboarding costs for new HIO participants can run anywhere from $5,000 to $10,000 for an individual provider to $150,000 for a complex hospital system, and have proved to be a meaningful barrier to HIOs' ability to scale, especially in the safety net. This incentive funding will help lower the barrier for providers to participate in data-exchange efforts across the state. The funds are also earmarked to connect all regional HIOs to the Controlled Substance Utilization Review and Evaluation System (CURES) database, another activity that can enhance the value HIOs offer potential participants.

Additionally, CMS has also approved another $40 million of funding to onboard emergency medical services (EMS) providers into regional HIOs. The availability of this approved federal funding is contingent upon The California EMS Authority finding matching state funds.

The Potential of TEFCA

In 2018, the Office of the National Coordinator for Health Information Technology within the Department of Health and Human Services proposed the Trusted Exchange Framework and Common Agreement (TEFCA), a regulatory instrument intended to implement certain of the interoperability requirements of the 21st Century Cures Act of 2016. TEFCA is a detailed and complex proposal, but, in essence, it seeks to establish a technical and governance framework that enables nationwide patient-data sharing across the large number of HIOs (regional and otherwise) that currently operate around the country. If successful, TEFCA would establish a single national "coordinating entity" that would develop and operationalize policies and procedures for the designation of "Qualified Health Information Networks" (the participating HIOs), for the terms of participation for individual provider organizations in such networks, and for the exchange of data among such networks.

TEFCA is in its early stages and still undergoing the rule-making process, including revisions in response to initial public comments. It is also currently formulated as an entirely voluntary framework, in which HIOs and their participating provider organizations can choose to participate or not. However, were TEFCA to be widely adopted in its currently proposed form, it would significantly extend the breadth and scope of patient-data sharing that is available to participants in HIOs, as well as standardize the rules under which existing HIOs operate.

Fast Healthcare Interoperability Resources (FHIR)

FHIR is a set of standards for creating web-based application programming interfaces (APIs) to read data from and write data to clinical information systems. The standards define what clinical data may be read from and written to systems, the degree to which those data are structured and coded, and how commands to read and write data should be formulated.

Although FHIR is a potent new technology to facilitate health-data interoperability, it is important to understand that FHIR only provides a tool kit for building data interfaces. It does not provide anything close to plug-and-play interfaces for exchanging patient data. Health Level Seven International (HL7)'s FHIR specifications are both quite generic and greatly extensible, so two provider organizations that both implement FHIR-compliant interfaces may do so in very different ways that are not consistent and do not result in semantic interoperability.

To address this lack of specificity, certain "profiles" have been developed based on the FHIR standard, and these profiles put greater constraints on how clinical data that are exchanged using FHIR must be structured, populated, and coded. Prominent examples of such profiles include the "Argonaut" profile (developed by a consortium of EHR vendors) and the "HL7 US Core" profile (developed to support interoperability needed under the federal meaningful use program). These profiles help to ensure that interfaces using FHIR will be able to exchange patient data meaningfully, and are an important step in the right direction, but they still have significant shortcomings.

First, these profiles still leave room for substantial variation in the way that data interfaces are implemented by different organizations, which continues to limit semantic interoperability. Furthermore, very few commercial EHR vendors have implemented the profiles faithfully (i.e., in full compliance with their technical specifications). Such compliance is not now required under the meaningful use EHR certification program or any other regulatory mandate. As such, despite the existence of the profiles, the FHIR implementations of leading EHR vendors remain technically different.

With regard to HIE, the FHIR standard and FHIR profiles provide only part of the functionality needed to support patient-data exchange among independent health care organizations. FHIR is particularly well suited to enable one computer application to access structured data from another over the internet and to manage the user-authentication and access-control aspects of doing that. However, it lacks facilities for supporting other important requirements for HIE across independent organizations, such as patient-identity management, patient record-locator services, provider directories, data-aggregation and normalization resources, and facilities for the type of "push" messaging needed for event-notification and referral-management applications.

Blockchain

"Distributed ledger" (DL) technologies, such as blockchain, have received a great deal of attention recently, including in the health care industry. At their core, these technologies define a distributed database system that (1) is not controlled or maintained by any single entity, (2) maintains a single, chronologically sequenced record of events, and (3) includes facilities to verify the authenticity of recorded events and to prevent the creation of alternative, inauthentic records, despite the decentralized nature of the system.

DL technologies have interesting properties with potential for applicability in health care, but the IT and health care industries are still very much in the early stages of exploring how these technologies may be used. To date, the hype surrounding DL technologies in health care far exceeds the number of demonstrably useful applications. It very much remains to be seen if DL technologies can solve problems related to HIE in a better way than alternative, preexisting technologies, such as traditional database models, security models, data standards, APIs, etc.

Consumer-Mediated Health Information Exchange

Efforts to give patients a greater role and greater control in the sharing of their health information have been underway for over 10 years. These forays into "consumer-mediated health information exchange" have primarily taken the form of personal health records (PHRs), such as Microsoft HealthVault, Google Health (now defunct), and various PHR initiatives sponsored by health insurers. To date, these approaches have enjoyed limited uptake among consumers, largely due to interoperability barriers that impede consumers' ability to conveniently aggregate and integrate their health data from the numerous provider organizations where these data originate. A recently launched initiative in consumer-mediated HIE from Apple, however, may be able to overcome these barriers.

Apple's Health Records enables patients to consolidate their medical data on their iPhones by directly interfacing these devices to the EHR systems of participating health care organizations using the FHIR API standards. To date, several hundred health care facilities have implemented interfaces to support Health Records. Patients authenticate to the health care facilities using their existing passwords for the organizations' PHR systems. Once authenticated, patients can download specified data available in their PHRs to their iPhones and can instruct Health Records to update these data automatically when additions or changes are made in their PHRs.

Notably, the medical data accessed by Health Records is transmitted directly from a provider organization to the patient's iPhone. It does not pass through nor is it stored in any servers operated by Apple or other third parties (other than backed up in encrypted form in iCloud, if desired by the patient, just as other iPhone data may be). Health Records is also able to interface with other compatible health care applications that patients download to their iPhones. Such applications may be obtained from any third-party app developer. After downloading such an app, a patient must explicitly authorize the app to access her medical data from the Health Records database and agree to any terms of service and terms of data usage presented by that app. After the patient does so, the app may then access her data and process, store, or transmit the data in whatever ways are authorized by the app's terms of service.

Health Records is a potentially significant development for several reasons. First, many provider organizations and their EHR vendors seem willing to technically support interoperability with the Health Records platform, which may eventually allow most patients to aggregate clinical data from most of their health care providers on their iPhone. This would be a first, despite longstanding efforts by PHR vendors, insurance companies, medical record-banking organizations, and others to build patient-centric health record systems. Apple's market share in smart phones combined with EHR vendors' widespread support for FHIR APIs has apparently enabled Apple to build data interfaces to a great many distinct provider organizations. This capability could significantly empower patients to better manage their own and their family's health, to more easily change health care providers, and to more easily seek second opinions, among other benefits.

Second, the ability of third-party apps to access data on and transmit data from patients' iPhones also creates the potential for iPhones to serve, effectively, as universal data-interface devices. Using Health Records, any third party could collect and store clinical data on a large cohort of (consenting) patients without having to build any interfaces to individual provider organizations. Such a universal interface could enable a host of new services and data-analytic capabilities with benefits for patients, providers, insurers, researchers, drug developers, public health agencies, marketers, and others.

Third, once downloaded onto a patient's iPhone, medical data are no longer subject to any protections under the Health Insurance Portability and Accountability Act (HIPAA) and other privacy regulations, leaving consumers responsible for understanding and assessing the risks as well as the benefits of granting third parties access to their medical data through Health Records. The capabilities enabled by Health Records may even necessitate additional consumer protections to prevent abuses of this new channel for patient-data access and sharing.

Given the potential benefits of enabling patients to aggregate and control their own health data, other technology firms, such as Seqster and Ciitizen, are currently pursing similar strategies.

Conclusion

In California, at-risk organizations, including commercial payers, Medi-Cal managed care plans, and ACOs, are increasingly recognizing that health information exchange is a critical functionality for care coordination and population-health management. The degree to which provider organizations move away from fee-for-service models and toward risk-sharing arrangements, such as ACOs and bundled-payment programs, will influence the demand for clinical integration and data analytics across independent organizations. Such demand, in turn, will increase demand for the types of HIE services that can be provided by regional HIOs. This is particularly true in the safety net and in regions where there is less provider consolidation and entities are therefore less likely to have EHR-mediated or other private data-exchange options.

To be well positioned to meet that demand, regional HIOs need to be ready with robust features, and large and diverse participant networks, as well as stable financial footing. While regional HIOs have plenty of work to do — for example, developing high-value features and prioritizing integrating their services with EHR products — they also require support from the many other stakeholders that will benefit from a successful and sustainable HIO network. Without that network, California's delivery system will likely remain unevenly and inequitably connected — a costly prospect for both the state and its patients.

Endnotes

1. Paul T. Cheung et al., “National Study of Barriers to Timely Primary Care and Emergency Department Utilization Among Medicaid Beneficiaries,” *Annals of Emergency Medicine* 60, no. 1 (July 2012); 4–10.e2, accessed December 14, 2018, https://doi.org/10.1016/j.annemergmed.2012.01.035.
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3. Nir Menachemi et al., “The Benefits of Health Information Exchange: An Updated Systematic Review,” *Journal of the American Medical Informatics Association* 25, no. 9 (September 1, 2018): 1259–65.