

A decorative graphic on the left side of the page features a large white circle that is partially cut off by the left edge. The circle is set against a background of four colored quadrants: dark blue (top-left), teal (top-right), orange (bottom-left), and white (bottom-right).

## Designing a Statewide Health Data Network: What California Can Learn from Other States

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## About the Author

**HealthTech Solutions** (HealthTech) was formed with a vision of supporting federal and state government agencies and health information exchange organizations with consulting and technical services to develop and implement state-of-the-art technology solutions and practices. Since 2011, HealthTech has been providing services to state Medicaid and Health and Human Services agencies, Fortune 500 companies, and agencies within the US Department for Health and Human Services. Authors include Sandeep Kapoor, president; JoAnne Hawkins, senior consultant; and Dawn R. Gallagher, senior consultant.

## Acknowledgments

The authors wish to thank the individuals and groups who agreed to participate and be interviewed for this paper, including representatives from the states profiled and California stakeholders who provided valuable insights on the health data exchange environment in California. A complete list of participants is included as Appendix C.

## About the Foundation

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

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

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### ABOUT THE SERIES

This is the first in a series of reports sponsored by CHCF aimed at helping inform California decision-makers about statewide data exchange. Other reports will focus on high-priority areas that require significant improvement in data exchange and on the existing electronic health record networks, regional health information organizations, and competing infrastructure that currently exist in California.

# Executive Summary

The COVID-19 pandemic has brought into stark relief the need for high-quality health data about everyone in the state. Creating and exchanging data more efficiently could allow health care payers, providers, and public health agencies to accurately target high-priority populations in need of vaccinations, allow contact tracers to quickly reach patients with positive test results, assist local governments and public health agencies in spotting early signs of outbreaks, and help researchers learn which treatments are working.

Even though millions of patient health records are shared electronically in California each day, health data do not flow across large areas of California, and access is limited in the areas that do share patient records. A highly fragmented system confines most data exchange to regional, community-based health information organizations (HIOs) and private health care networks.<sup>1</sup> And many kinds of health care records are likely left out, including those from behavioral health providers, social service organizations, and nursing homes, as well as those from out-of-state care providers.<sup>2</sup>

Overcoming these shortcomings would reduce health care disparities, improve patient safety and public health, and reduce wasteful spending, poor coordination, and reactive care.<sup>3</sup>

This report explores what is working in four states that have successfully implemented statewide health data networks. The report broadly defines a statewide health data network as a state's approach to data exchange that allows *all* health care providers, institutions, and agencies across a state to appropriately access and securely share patient health information electronically. Further, the term is more expansively defined in this report to address the direction in which many statewide health data networks are moving, which is to also connect clinical and claims records, as well as data about behavioral health care and social determinants of health (SDoH) to enable "whole-person care."<sup>4</sup>

Each state in this report may brand its system differently, calling its statewide health data networks *health information exchanges* (HIEs) or *health information networks* (HINs), and may have followed a slightly different path to development over time, but all have important features in common. The "framework for success" that these four states have forged offers lessons for California in how to institute new technology and expand data exchange statewide.

## The Role of New Federal Regulations and Funding in Data Sharing

In addition to expanding data sharing to better respond to COVID-19 and other identified needs, new federal regulations that take effect as early as 2021 will dramatically reshape the landscape and create an opportunity for California to act. In 2020, the federal government instituted new standards and requirements for expanding data sharing, such as requiring hospitals to notify primary care providers when hospitals admit, discharge, or transfer (ADT) patients; requiring health plans and payers (including Medicaid) to make patient data available; allowing patients to access a single, complete health record from all their providers and health plans; and allowing patients and care teams to access a list of health plan providers, and eventually, telling them which providers are accepting new patients.<sup>5</sup> The goal of the federal regulations is to ensure that a greater amount of data flows through the delivery system and is broadly accessible to improve patient and public health outcomes, while maintaining strict privacy and security standards.

The cost to build or improve the technology to meet the federal mandates falls on the affected entities, such as the electronic health record (EHR) vendors, hospitals, or payers.<sup>6</sup> However, there is significant federal funding, ranging from 50% to 100% of the cost, available to state Medicaid agencies for planning and implementing systems to be in compliance with Medicaid regulations. There are two requirements to get the federal funding: (1) Funding is only available

for those costs of the project that benefit the Medicaid population and (2) to be eligible for federal funds, accountability and oversight that show if the statewide health data network is meeting the benchmarks and outcomes outlined in the grant documents must rest with a state entity like health and human services (HHS) that includes the state's Medicaid agency.<sup>7</sup> The COVID-19 relief funds also create another opportunity to draw down federal funds to advance a statewide health data network.<sup>8</sup> Although these funds are targeted, they can be leveraged to develop a statewide health data network that addresses the data-sharing needs of the safety net as well as public health emergencies like COVID-19 response.

The four states covered in this report received federal Medicaid funding for their statewide health data networks because governance of the network includes state leadership and direction, which provides coordination and direction that otherwise isn't available today to the existing landscape of RHIOs and EHR-based private exchanges. The funding provides California with an opportunity to act boldly and expansively in creating a unified California health data network.

Given the already huge investment in the exchange of health data in California, the primary issue is how California can build on existing efforts to best ensure that a patient's entire medical, behavioral, and social care team can access patient health data when and where needed, safely and securely. This report addresses that foundational issue by examining:

- ▶ The governance and operating models and data frameworks that exist in four states — Michigan, Maryland, Nebraska, and New York — that have implemented robust statewide health data networks.
- ▶ The ways in which each of these states expanded from simply sharing patient clinical data to addressing high-priority needs, such as COVID-19 response and care coordination statewide, thus adding value to local and regional network systems.

- ▶ The lessons these states offer California as it considers a statewide health data network to meet future needs.

Interviews took place with leaders within each statewide data network, as well as HIO, Medicaid, and delivery system leaders, to draw lessons on how California can overcome challenges and innovate in data exchange.

## Four States with Robust Statewide Health Data Networks

Michigan, Maryland, Nebraska, and New York are nationally recognized as having robust statewide health data networks that ensure access to a nearly complete record of a patient's health care data timely and securely.<sup>9</sup>

**Governance.** State governments play a significant leadership role in these networks. Maryland, Michigan, and New York each passed legislation that assigned regulatory responsibility to a state agency like the state's human services agency and a board that sets policies and priorities for the health data network. Because Nebraska's health data network was born before significant federal funding for the development of these health data networks, Nebraska's network operates under a partnership agreement with the state's human services department and has its own operating board that includes members of the state. Ultimately, each state has a multistakeholder board with representatives from the public, nonprofit, and private sectors to guide policies and priorities.

**Data model.** While each state took a different approach to whether just one HIE or multiple networks send data to a central hub, and whether they centrally store data or not, all the statewide health data models provide a minimum backbone that includes a master patient index to accurately match records to the right patient for data that flow through their systems. Nationally, three basic models exist for accessing, storing, and using data. They are referred to as (1) *centralized*, with centralized governance and

a data warehouse that stores and transmits data; (2) *decentralized*, with network participants agreeing to support policies; and (3) *hybrid*, with a network-of-networks system and a central hub that either uses a data warehouse or acts as a data highway to exchange data without storing it. Nebraska features a centralized data warehouse with common standards. Maryland's hybrid network features a cloud-based data warehouse that stores all network data and places some policy-setting and governance at the individual network level. The hybrid networks of Michigan and New York feature "data highways" that carry, but do not permanently store, all data. All the states report that the size of the population does not affect their network capacity.

**Participation incentives.** Each state uses a mix of encouraging voluntary participation along with regulatory rulemaking and statutory mandates to get participation in HIOs or the health data network.<sup>10</sup> In Maryland, payers are required to submit claims data to an all-payer claims database (APCD), which is integrated with clinical records through the Chesapeake Regional Information System for our Patients (CRISP). Maryland requires all health plans, and other entities that aggregate and exchange data, to allow outside providers access to their networks only if the hub network certifies that they meet certain standards to comply with state policies. Medicaid and managed care organizations also participate in a shared savings plan distributed, in part, based on CRISP use.

In Michigan, participation is also voluntary, but all payers including Medicaid contribute to a financial pool, redistributed only to MiHIN (Michigan Health Information Network) participants based on performance milestones.

New York's Department of Health has promulgated regulations that require certain providers with certified EHRs to exchange data with a qualified entity (QE) or Statewide Health Information for New York (SHIN-NY). New York has also maintained a Data Exchange Incentive Program (DEIP), managed by the New York eHealth Collaborative (NYeC), that helps to offset providers' costs of connecting to the network.

Nebraska has a state statute that mandates participation. Nebraska's network also houses the state's Prescription Drug Monitoring Program (PDMP) database, which prescribers and dispensers are required to check before certain types of opioid drugs can be prescribed or dispensed. The Nebraska database is unique because it includes all prescribed medications, not just opioid drugs, and provides a full medication history. The requirement to check a PDMP greatly increases participation in the larger health data network. Soon, all state Medicaid agencies will be required to have an authorized PDMP registry that prescribers and dispensers of prescription drugs must check before prescribing or dispensing certain opioid drugs.

**Coverage of high-priority needs.** The health data networks profiled in this report were initially built for providers to share patient data with other providers via their EHRs. The desire to improve health outcomes at the patient and public health levels resulted in these mature networks developing tools for specific health needs, known as "use case" solutions, which collectively have driven the expansion of health data networks. These four networks incrementally implemented a few use case solutions that stakeholders agreed would require statewide data exchange, such as:

- ▶ **Meeting federal requirements.** Hospitals use health data networks to send ADT notifications to primary care providers when their patient gets admitted, discharged, or transferred to or from a hospital, which will soon become a federal government requirement for all hospitals.
- ▶ **Responding to the COVID-19 pandemic.** Due to their maturity and statewide coverage, the networks profiled in this report have greatly assisted states' pandemic responses. COVID-19 test results flow to public health agencies and the statewide network, which report COVID-19 data and lab results to providers and patients. The networks also gather and map COVID-19 test results by zip code and gather other patient characteristics such as race, ethnicity, and income; assemble inventory levels for personal protective equipment; and create real-time reports

about bed utilization from ADT feeds to assist with patient transfers.

- ▶ **Helping systems talk with each other.** Statewide networks standardize and translate data coming into the system to ensure data going out follow a format that all participants can view. The statewide networks use a master patient index to ensure that the right patient is matched up with the right records, even when the systems use slightly different spellings of a patient's name.

**Scale.** All of these networks have achieved significant scale that has not affected their capacity. New York boasts a statewide health data network that has more than enough capacity to cover the state's almost 20 million residents, proving that these types of networks can work at scale in high-population states like California. While significantly less populated, Maryland, Nebraska, and Michigan operate statewide and provide health data networks for other states in their region, which helps with financial sustainability and creates economies of scale. Maryland's network allows each type of participant or geographic jurisdiction to determine the data it will share. This mitigates privacy and security concerns, and also the issues some health plans or hospital networks have had about their data being accessible by competitors.<sup>11</sup>

## A Framework for Success

The experience of these four states offers initial insights for policymakers to consider as they work to implement a statewide health data network in California. The insights provide a framework with three features:

- ▶ **The state takes a strong leadership role.** Maryland and New York used statute to grant formal authority to state entity while Michigan used statute to create a commission that works with a state entity to establish the statewide health data network.<sup>12</sup> The state entity plays a significant role in setting data-use priorities, using the agency's authority to encourage or mandate network participation, and drawing down

federal funds to support data exchange activities. Whether the network is centralized, decentralized, or hybrid is a secondary decision to which entity governs its implementation.

- ▶ **A multistakeholder body with public, nonprofit, and private business representation provides operational oversight.** In Maryland and Michigan, state statute defines the composition and role of the operational entity, including participation by the state authority. In New York, regulations define the framework and parameters of operational oversight; the regulation does not name an entity but allows the state to select one. This public-private structure enables states to work incrementally to build trust and establish minimum standards for data exchange while acknowledging the importance of a variety of perspectives including business needs, public health, and patient privacy.
- ▶ **The network taps public and private funding.** Each statewide network profiled in this report leveraged federal funding for planning and implementing its health data network, and still requires that funding to be sustainable. These states receive 50% to 80% of their financial resources from federal and state sources.<sup>13</sup> To be eligible for federal funds, accountability and direction for the statewide health data network must rest with a state entity like HHS that includes the state's Medicaid agency. The availability of COVID-19 relief funds (through the Coronavirus Relief Fund) provides another opportunity to draw down federal funds to advance a statewide health data exchange. Local or regional HIOs and large hospital networks generally cannot tap direct federal funding and must seek other ways to recover or absorb the costs.



## What California Can Learn from Other States

Despite California's large size and its wide variety of approaches to health data exchange, the leaders of other states who were interviewed for this report did not see those issues as insurmountable. The interviewees saw the question as not *if* California will act, but rather *how* the state will create a health data network that benefits all Californians.

Based on lessons learned from implementing other statewide networks, interviewees offered both high-level and tactical suggestions for California to consider:

- ▶ Establish a statutory leadership role for state government. Keep the statute to top-tier policy issues such as governance, participation by providers and payers, consumer access to the data, data privacy, and financing. The statute should describe the state role and the role of private and public partners in administration and operation of the network.
- ▶ Build in a mechanism for broad stakeholder participation, oversight, and accountability.
- ▶ Recognize that use cases must drive the expansion of health information exchange over time. Incrementally implement solutions, starting with a problem most people believe should be addressed. Move from planning to action by identifying a unified agenda and priorities among private and public entities and working to apply that agenda to the execution of a state framework.
- ▶ Provide incentives for participation in the networks and use enforcement "sticks" for entities that do not fully participate. Consider participating in or organizing payer pools, and charging fees for participation and value-added services to promote greater participation and sustainability.
- ▶ Take full advantage of federal funding, including funds from the Health Information Technology for Economic and Clinical Health (HITECH) Act,<sup>14</sup> the Coronavirus Aid, Relief, and Economic Security (CARES) Act,<sup>15</sup> and the Coronavirus Relief Fund (CRF),<sup>16</sup> for investment in data exchange capabilities and infrastructure.

## The Future of a Statewide Health Data Network in California

While new federal requirements are expected to greatly expand health data networks nationwide, the leaders interviewed believe that states will play a major role, in part because states will be able to leverage federal funds to meet the requirements. Twelve years ago, California embarked on an effort that did not come to fruition, partly because the state and a range of stakeholders were not ready to coalesce around a vision for what a health data network could and should be.

A great deal has changed since then in technologies, federal requirements and funding, and urgent public health needs. In California, a consensus is emerging to once again consider whether and how to implement a statewide health data network. Practical lessons learned from robust statewide efforts in the four states profiled can offer decisionmakers important insights about how to achieve the benefits that widescale access to health data offers to all Californians.

# Introduction

This report is the first in a series sponsored by the California Health Care Foundation (CHCF) to help inform decisionmakers in California about why better health data exchange is important, what efforts and infrastructure for the sharing of health data currently exist in California, and what models for statewide health data networks exist nationally and could be viable in the state.

The report examines statewide health data networks in Michigan, Maryland, Nebraska, and New York. Each of these networks is nationally known to have achieved robust statewide electronic access, timely and securely, to a patient's health data when and where needed.

Statewide health data networks allow all health care providers, institutions, and agencies across a state to appropriately access and securely share patient health information electronically. The term is defined more expansively in this report to include networks that connect clinical and claims records as well as data about behavioral health care, social determinants of health (SDoH), "whole-person care," and other forms of health-related information.

The data in these networks generally originate in a patient's electronic health record (EHR), which records demographic and clinical patient data such as blood pressure, health conditions, treatments, and more recently, immunizations, vaccinations, or information about SDoH like homelessness or food insecurity. Larger hospital systems or health plans typically have their own private local and regional health data networks in which health care professionals, care managers, and billing units store and access patient records, although they do not connect with every provider, institution, and agency like a statewide health data network can.<sup>17</sup> Providers with EHRs connected to these networks generally have more patient health data available to them, which can be critical during public health emergencies such as the COVID-19 pandemic. Information flowing to and from a statewide health data network can be available to public health

agencies, patients, and providers, including emergency responders.

The electronic exchange of health data helps facilitate coordinated patient care, reduce duplicative treatments and services, and avoid costly mistakes.<sup>18</sup> Health data from doctor visits and test results get updated each time a patient visits a health provider. Using health data networks, a provider can receive a list of patients with heart disease, for example, which they can use to locate patients who need immediate care and schedule follow-up appointments.

Recent federal rules will require payers to build and maintain systems that allow patients easy access to their data to better control decisions about their health, which can be easier when all their records are accessible through a single portal.<sup>19</sup>

The exchange of health data is vital for patient and public health. Given California's huge investment in the adoption of health information technology (HIT), spurred on by significant federal funds, the state must ensure that data captured in HIT systems are made available at the right level, at the right time, to the right people.

The possibility of implementing a statewide health data network in California has recently grown closer to reality. As California decisionmakers explore their options, it is vital that they consider a framework for success that other states have forged as they implemented their own statewide networks.

This report examines:

- ▶ The governance and operating models and data frameworks that exist in four states — Michigan, Maryland, Nebraska, and New York — that have implemented robust statewide health data networks. (See "Three Data Models" on page 9.)
- ▶ The framework for success that each of these states has used to add value to local and regional systems and to expand data exchange from simply sharing



## Three Data Models

The technology model that a health data network chooses fundamentally shapes how it collects, organizes, and exchanges its data, and therefore which use cases it can offer its members. Three basic models for statewide health data networks have emerged over the years, with centralized and decentralized approaches on either end of a spectrum, and a hybrid “network-of-networks” approach at the center.



**Centralized Model.** Operates like a “hub and spoke” whereby data are aggregated and managed centrally. The health data network is responsible for operating the centralized technology and making information available to participants for purposes agreed to by those participants.

### ADVANTAGES

- ▶ Uses one consistent privacy consent approach
- ▶ Less expensive for a central repository to operate a data warehouse than for multiple organizations to maintain their own data
- ▶ Rich set of aggregated and consolidated patient data, enabling more analytical use cases

### CHALLENGES

- ▶ Difficult to normalize and standardize data
- ▶ More difficult to scale
- ▶ Requires greater trust among participants



**Hybrid Model.** Individual networks or groups of networks send data to a central hub, where data are shared with users. The hub can store the data in a data warehouse or can act as a “data highway” that carries information without storing it. At a minimum, its technology centralizes some patient data and functionalities, like identities and record locator services.

### ADVANTAGES

- ▶ May be more scalable than the centralized model because reducing the number of sources of data reduces the amount of data normalization and standardization needed
- ▶ Allows participants to leverage existing investments in data-sharing technologies, allowing for more buy-in earlier

### CHALLENGE

- ▶ More costly overall to sustain multiple platforms that perform the same function, like data normalization



**Decentralized Model.** An organization generally acts as a facilitator that convenes participant networks to set policies and regulations and creates mechanisms for participants to connect to each other and to share patient health records. Members primarily consist of regional health data networks, state agencies, and provider health systems. California essentially has this model today, with the California Trusted Exchange Network facilitating agreed-upon standards for data sharing across its members. The decentralized model is rarely found in other states, and no statewide decentralized model exists.

### ADVANTAGES

- ▶ Minimizes privacy issues, because data are housed in each individually secured health data network
- ▶ Takes advantage of existing network infrastructure investments

### CHALLENGES

- ▶ Can be more expensive to exchange information across networks because no standard mechanism for exchange exists
- ▶ Offers a less formal governance mechanism without real accountability
- ▶ No assurance of statewide coverage

patient clinical data to implementing solutions addressing high-priority needs, or “use cases,” such as COVID-19 response and care coordination.

- ▶ The state’s current delivery system, regulatory environment, technology infrastructure, and investments made in health information exchange.
- ▶ The lessons learned that these states offer to California as decisionmakers consider implementing a statewide health data network, specifically one that acknowledges the state’s current delivery system, regulatory environment, technology infrastructure, and investments made in health information exchange.

## A Brief History of Health Data Networks

In 2009, the Office of the National Coordinator for Health Information Technology (ONC) started a five-year program that provided hundreds of millions of dollars in 100% federal funding for states to build what the ONC termed health information exchanges (HIEs).<sup>20</sup> The ONC encouraged states to establish an Office of the State Coordinator to oversee the state’s health information technology efforts. States could either operate their own HIEs or partner with nonprofit or for-profit organizations to build and operate HIEs. Nearly every state partnered with a nonprofit entity to operate the HIE. States were also encouraged to name a state designated entity (SDE), in most cases also the HIE, to oversee and establish appropriate privacy and security safeguards and other policies and standards. The four statewide data health networks covered in this paper are SDEs.<sup>21</sup>

The federal government predicted that once it had infused substantial funding into fortifying and connecting EHRs and HIEs, the networks would become sustainable without significant additional federal funding. But to get providers to connect to networks early on, many networks did not charge fees, and if they did, the fees were not enough to cover operating expenses. When federal funding for health data

networks ended in 2014, some exchanges went out of business while others consolidated. Since 2011, the number of HIEs has fallen by almost half.<sup>22</sup> Federal funding is still available at reduced levels and is generally only available through a Medicaid agency requesting funding for very specific projects that meet US Centers for Medicare & Medicaid Services (CMS) requirements as described later in this report.

## New Federal Rules Create an Opportunity for California to Act

New federal regulations that go into effect as early as 2021 will dramatically reshape the landscape. In 2020, the federal government instituted new standards and rules for EHRs, hospitals, and health care providers. These rules impose mandates on payers, including all health plans and state Medicaid programs.

The goal of the regulations is to ensure that a greater amount of data flow through the delivery system and is broadly accessible, to improve patient and public health outcomes while maintaining strict privacy and security standards. The following summarizes high-level key requirements for stakeholders:<sup>23</sup>

### EHR vendors:

- ▶ **Interoperability.** To be certified, all EHR vendors must have compatible systems, together known as “interoperability.”

### Payers (including all Medicare and Medicaid program entities):

- ▶ **Patient access APIs.** Entities are required to have an electronic system that allows patients to easily access their health and claims records using an electronic device of their choosing.
- ▶ **Provider directory APIs.** Entities are required to have an electronic system for patients and caregivers to access a master index of providers under contract or agreement, and eventually, to identify providers accepting new patients.

- ▶ *Portability of patient records.* When patients move from one payer to another, the previous payer(s) must provide health records and claims to the new payer upon request. Eventually, a complete health and claims record is established.

#### Providers:

- ▶ *Information blocking.* Providers, health plans, and payers are prohibited from blocking patient health information from being shared with other health care providers and payers.
- ▶ *Prescription Drug Monitoring Program (PDMP).* Under the 2018 federal Substance Use Disorder Prevention that Promotes Opioid Recovery and Treatment for Patients and Communities (SUPPORT) Act, state Medicaid agencies must have an authorized PDMP registry, and prescribers and dispensers of prescription drugs must check the PDMP before prescribing or dispensing certain opioid drugs.
- ▶ *Admit, discharge, or transfer (ADT).* All hospitals must send an electronic notification to a patient's primary care provider or care team when a patient gets admitted, discharged, or transferred to and from a hospital.

Each of the entities that fall under the rules must pay for the tools and systems that perform the mandated functions. However, federal funding ranging from 50% to 100% of the cost is available to Medicaid agencies for the portion of the costs of planning and implementing tools and systems that benefit the Medicaid population.<sup>24</sup> Agencies can access federal funds only if a state Medicaid entity retains accountability and direction over the systems. The four statewide health data networks covered in this report can get the Medicaid federal funding because their state's Medicaid agency maintains accountability and direction over the HIE contracts to build the necessary tools and systems.<sup>25</sup>

While direct federal funding for mandates imposed on EHR vendors, hospitals, and private plans and payers is not available through a state Medicaid agency, given that federal funds are available to Medi-Cal for Medicaid projects that meet federal requirements,

leaders from the four states interviewed for this report stressed that California should take this opportunity to assess how a statewide health data network could meet the Medicaid mandates in a cost-effective way while also providing opportunities to indirectly reduce the costs for hospitals, providers, private payers, and health plans. (See Appendix B for more details on federal funding opportunities for Medicaid-related projects.)

## Four States with Robust Statewide Health Data Networks

This section examines Michigan, Maryland, Nebraska, and New York — four states nationally recognized as having robust statewide health data networks, known in these states as health information exchanges (HIEs). Each ensures access to a nearly complete record of a patient's health care data in a timely and secure way.<sup>26</sup> Table 1 summarizes characteristics of the four statewide networks examined in this report (see page 12).<sup>27</sup>

### Michigan

The Michigan Health Information Network (MiHIN) is a hybrid statewide health data network.<sup>28</sup> Its central hub moves data and stores data for a limited period of time. When MiHIN began, Michigan had a fragmented system of networks similar to what California has now. Over the years, the networks consolidated and MiHIN's hub became the vehicle for exchange.

#### Originating Authority and Oversight

In 2006 Michigan law established the Health Information Technology Commission (HITC) which, with Michigan Department of Health and Human Services (MDHHS) participation, created MiHIN, a network-of-networks collaborative. The HITC designed MiHIN to be a 501(c)(3) entity that contracted with the state for services the state required, including statewide data exchange, and could provide additional services to other participants and customers.

**Table 1. Characteristics of Four Statewide Health Data Networks**

|  | MICHIGAN<br>(MIHIN)   | MARYLAND<br>(CRISP)   | NEBRASKA<br>(CYNCHALTH)  | NEW YORK<br>(SHIN-NY)   |
|--|---|---|--|---|
| <b>Originating Authority for the Creation of the Health Data Network</b> | Statute established an HIT Commission, which, with the participation of the Michigan Dept. of Health and Human Services (DHHS), established the independent HIE.  | Statute directed an existing independent state agency (Maryland Health Care Commission [MHCC]) to issue an RFP and establish a health data network across HIOs.   | Market driven. CyncHealth was originally formed by payers. With availability of HITECH funds for developing HIEs, DHHS partnered with CyncHealth through contracts and agreements to expand use cases and the network. CyncHealth operates as a private nonprofit 501(c)(3). | Statute established a directive to the Department of Health (DOH) to establish a statewide network and set requirements in regulation for operating a qualified entity (the regional HIOs) and the statewide governance and technical operations. |
| <b>Entity with Formal Regulatory Authority over the Network</b>          | DHHS collaborates with MiHIN and manages any grant or contract work it elects to award MiHIN.   | Maryland Health Care Commission has regulatory authority.   | No formal state regulatory authority over CyncHealth, but DHHS promulgated rules that require provider participation for some operations in CyncHealth.  | DOH has regulatory authority over SHIN-NY.  |
| <b>State-Established Oversight Board</b>                                 | Statute created the Health Information Technology Commission and identified 13 public and private members that advise on policy and priorities for MiHIN. MiHIN routinely presents at this forum.   | Same board for the Maryland Health Care Commission.   | None. Statewide policies and priorities developed in collaboration between CyncHealth and DHHS.  | The DOH relies upon the New York eHealth Collaborative (NYeC), a 501(c)(3) to assist with governance of the network and contracting with the QEs for services.  |
| <b>Day-to-Day Operational Governance</b>                                 | MiHIN has its own operating board for operational decisions.<br><br>MiHIN also created the MiHIN Operations and Advisory Committee to advise on use case development.   | CRISP has its own operating board for operational decisions.<br><br>CRISP also has a board of advisors and five advisory committees to provide guidance and input.  | CyncHealth has its own operating board for operational decisions, which includes DHHS members.<br><br>CyncHealth also has several advisory committees to provide guidance.   | QEs have independent operating boards. NYeC serves as the operational board for SHIN-NY, and there are numerous committees that support that work.  |
| <b>Levers to Encourage Participation</b>                                 | Medicaid requires health plans to incent providers to participate in statewide use cases (versus participate in HIOs). In response, Medicaid and commercial health plans have created a pool of funds for organizations to participate and conform their data to specific high-value use cases advanced by MiHIN. | MHCC requires APCD submissions linked to CRISP clinical data.<br><br>Health Services Cost Review Commission requires data submission to CRISP to measure hospital-specific performance.<br><br>Medicaid and managed care organizations participate in a shared savings plan distributed, in part, based on CRISP use. | Statute requires opioid prescribers and dispensers to check the PDMP* run by CyncHealth.   | Regulation requires certain providers with certified EHRs to exchange with a QE/SHIN-NY.<br><br>The Data Exchange Incentive Program, managed by the NYeC, helps to offset providers' costs of connecting to the network.                          |
| <b>Privacy and Security</b>  | HITRUST certified <sup>†</sup>  | HITRUST certified <sup>†</sup>  | HITRUST certified <sup>†</sup>   | HITRUST certified, <sup>†</sup> state audits  |
| <b>Scope</b>   | Statewide (plus additional services outside the state)  | Statewide (plus WV, DC, and soon CT)  | Statewide (will soon add IA)   | Statewide   |

**Table 1. Characteristics of Four Statewide Health Data Networks, *continued***

|  | MICHIGAN<br>(MIHIN)  | MARYLAND<br>(CRISP)  | NEBRASKA<br>(CYNCHHEALTH)  | NEW YORK<br>(SHIN-NY)   |
|--|--|--|--|---|
| <b>Data Model</b>                            | Hybrid network with central hub that carries and stores data for a limited time, 100 days to 18 months, with an option to aggregate data for use cases that require longitudinal records or analyses.. | Hybrid network with central hub that carries and stores data.            | Centralized policies, standards, and data warehouse.   | Hybrid network with central hub “highway” that carries but does not store data.                             |
| <b>Largest Funding Sources</b>               | Federal, state, payers, and hospitals (user fees)  | Federal, state, payers, and providers (user fees)                        | Federal, state, payers, and grant funding  | Federal, state, payers, and providers (user fees)   |
| <b>Core Use Cases Added</b>                  | Over 37 use cases: ADTs, immunization, SDoH, patient provider attribution, master patient index, labs, and quality tools   | ADT notifications, PDMP, lab reporting                                   | DMP, quality reporting and analytics   | Patient record lookup, results delivery, master patient index, ADT notifications, quality measurement, etc. |
| <b>Use Cases Added for COVID-19 Response</b> | Receives lab tests and vaccination information and sends to providers ADTs and demographic links to identify, track and provide timely services.   | Enables statewide tracking and surveillance, notifications to providers. | Connects test centers to public health, sends test results to providers, offers demographic data for public health tracking. | Sends public health lab results to providers, offers demographic data for public health tracking.           |

\*A Prescription Drug Monitoring Program (PDMP) is an electronic database that prescribers and dispensers must check (beginning in 2021, under a 2019 federal law) before certain types of opioid drugs can be prescribed or dispensed.

† A national independent certification that demonstrates compliance with HIPAA (Health Insurance Portability and Accountability Act) and privacy standards.

From its inception, the vision was to coordinate data across the many local and regional HIOs in the state and add value to these networks by providing services that enabled and enhanced exchange at a statewide level. MiHIN was born out of HITC to deliver on that vision. The HITC is led by a 13-member public- and private-sector board that sets MiHIN’s policies and priorities. MiHIN’s day-to-day operations are governed by an 18-member MiHIN board, which consists of state officials and a representative from each of the individual system/network participants. MiHIN also has an operations advisory committee (MOAC) that handles use case development and support and management of technical working committees. It consists of subject matter experts.

### Data Model

MiHIN functions like a “highway” that carries data between systems and does not permanently retain patient records in a data warehouse. Rather, data are held for 100 days to 18 months, with optional data aggregation use case for longitudinal record and analytics. MiHIN also facilitates specific use cases, such as matching patients with records, as well as sending alerts to primary care providers when their patients visit the emergency department.

### Participation Incentives

While participation in MiHIN is voluntary, MDHHS requires Medicaid plans to incentivize providers to participate in the local HIOs. To this end, Michigan hospitals and payers (including Medicaid) pay into a pool based on the number of patients they serve. The pool pays providers who use the network a financial

share based on the quality of the data the provider submits through HIOs that connect to MiHIN and the provider's use of these systems.

Industry collaboratives like the Michigan Collaborative Quality Initiatives (CQIs) reinforce many of the state-wide objectives and services that MiHIN supports. For example, Blue Cross Blue Shield of Michigan (Blue Cross) provides incentives for participating HIOs connected to MiHIN through its CQIs. The initiatives involve partnerships among Blue Cross hospitals, physicians, and other stakeholders to address clinical program areas with high costs and varying quality outcomes.

### Coverage of High-Priority Needs

MiHIN's unique success stems from what it calls its "use case factory," an effort to identify and develop solutions targeted to specific health needs. The MiHIN advisory committee and technical teams work with Michigan's nonprofit and for-profit business leaders who recommend and prioritize the development of new use cases based on the challenges and opportunities they face. To date, MiHIN's use case factory boasts over 37 use cases developed to meet those specific challenges and opportunities that benefit providers, payers, and patients. Each new solution drives increased traffic and use of the network. MiHIN provides access to a core set of use case solutions with the basic participation fee, with enhanced services and use cases for participants who agree to pay for extra services.

The service offers solutions tailored to the following needs:

- ▶ **Meeting federal requirements.** Federal law will soon require all hospitals to send ADT notifications to all providers primarily responsible for a patient's care. MiHIN has already met that requirement for its participants — providers receive daily ADT and emergency room notifications for more than 70% of the state's 10 million residents.
- ▶ **Responding to the COVID-19 pandemic.** When COVID-19 tests are performed via drive-through, the local test center sends the data to the

public health agency, which in turn sends the data to MiHIN. The network sends test results to providers that have an active relationship with a patient. MiHIN's master patient index algorithm has been invaluable in the state's ability to identify, track, and provide services to COVID-19 patients timely and effectively.

- ▶ **Helping systems talk with each other.** MiHIN does not permanently store data, but it can accept and standardize information from providers working in disparate data formats and IT systems so the information becomes useful. For example, the health data networks created by local MCOs and health systems have unique methods of identifying patients, and differences between them prevent these networks from matching patients and their clinical information across systems. MiHIN overcomes this by providing a master patient index.

### The Future of Data Exchange in Michigan

MiHIN is a mature network and will focus over the next several years on how it can add even more value for Michigan health care participants. It plans specifically to work toward the following goals:

- ▶ Expand participation among community health organizations, social services agencies, correctional institutions, and auto insurers.
- ▶ Implement use cases that "follow the thread" of information flowing through the emergency department. For example, EMS responders will receive details about a person they interact with, such as a person's health conditions and medications, before they arrive on-site.
- ▶ Develop use cases that eliminate the duplication of efforts among Michigan's DHHS, public health agencies, department of education, hospitals, and specialty care providers. In some cases, public health requires providers to submit redundant documentation such as demographic information that is also submitted to DHHS. MiHIN is working to develop tools that auto-populate data across systems.



## Maryland

The Chesapeake Regional Information System for our Patients (CRISP) is a hybrid statewide health data network for Maryland.<sup>29</sup> CRISP has expanded its geographic footprint by becoming the statewide health data network for Washington, DC; West Virginia; and soon Connecticut.

### Originating Authority and Oversight

A statute designated an existing independent regulatory agency, the Maryland Health Care Commission (MHCC), to issue a request for proposals (RFP) to establish a statewide health data network that would coordinate data exchange across the state's existing data-sharing systems. The governor appoints 15 commissioners to govern MHCC, with the advice and consent of the Maryland Senate. The MHCC has a policy board that has oversight over and advises on statewide health data network activities.

CRISP was established as the state designated entity (SDE) under state law in response to the RFP. CRISP has its own operational board of directors that includes senior health care executives and a board of advisors that provides guidance and input, along with five operating committees.

### Data Model

CRISP is based on the hybrid model and centrally stores data from the participating networks. CRISP benefits from being cloud-based, allowing users to store and access data on internet servers without the need to build data repositories or warehouses on local IT systems. Cloud-based software makes scaling and updating the systems easier. Unlike traditional hardware and software, cloud computing helps organizations stay at the forefront of technology without having to make large investments in purchasing, operating, and maintaining equipment themselves.

### Participation Incentives

Decisions of two independent commissions in Maryland play a critical role in driving participation in CRISP.

The Health Services Cost Review Commission, an independent state agency that has regulated hospital rates since 1971, requires hospitals to connect to CRISP to enable measurement of hospital performance on readmissions. This requirement has resulted in hospitals, public health departments, and ambulatory providers having access to CRISP Reporting Services (CRS), a set of monthly reports that analyze hospital trends and utilization by linking hospital case mix data with unique patient identifiers. The quality reports are used to determine payments from the shared savings program.

The MHCC requires all health care payers to submit claims data to Maryland's all-payer claims database (APCD), including demographic and health care codes that identify the services and time billed for each claim. The claims data are integrated with clinical health records through CRISP, providing both clinical information on the health care services provided and administrative information on the amount paid for the service. This integration provides greater insight into, for example, hospitals or regions in which inpatient care or hospital readmissions happen more frequently and supports analysis by the Medicaid agency of which members tend to go the emergency room more often.

### Coverage of High-Priority Needs

CRISP has taken an incremental approach to introducing use cases over time. The top needs addressed include:

- ▶ **Helping meet federal requirements for ADT feeds.** CRISP allows hospitals to submit ADTs through CRISP, meeting this new federal requirement. A private company markets the alerts, bringing in additional revenues for the network.
- ▶ **Meeting PDMP requirements.** CRISP is fully integrated with the state's PDMP, which prescribers and dispensers are required to check before they issue opioid drugs. This allows the state to track controlled substance prescriptions and can provide health authorities timely information about prescribing and patient behaviors that contribute to the opioid epidemic.

► **Responding to the COVID-19 pandemic.** COVID-19 test results are reported by providers and labs into CRISP, which runs reports by zip code and sends the results to public health agencies. CRISP also receives reports from hospitals about inventory levels for personal protective equipment; these reports, too, are forwarded to public health agencies. CRISP's master patient index, which matches patient records throughout the system, uses positive COVID-19 results to report on disparities among groups, races, ethnicities, and income levels. This type of analysis allows the state to focus on high-priority groups and geographies, and to understand how to use data about disparities in care to better inform the public health response in high-priority areas.

► **Matching patients and records.** CRISP manages a master patient index that helps coordinate the sharing of data across its many data sources for all its use cases. It helps link claims data from the APCD to the clinical data already flowing through the system. It also supplies demographic data to better understand disparities among groups, races, ethnicities, and income levels. CRISP also creates a patient-specific identification number when a patient leaves one hospital and later is admitted to another hospital. CRISP uses the information to identify recurring visits.

### The Future of Data Exchange in Maryland

CRISP envisions further consolidation of health data networks across the country as some systems mature and offer more valuable services. To successfully accomplish this, statewide data networks like CRISP will move to standardize technology systems, data tools like master patient indexes, and important use cases, especially for issues that require coordination at scale such as COVID-19 response.

## Nebraska

CyncHealth is a centralized statewide health data network operating in Nebraska.<sup>30</sup>

### Originating Authority and Oversight

CyncHealth, formerly known as the Nebraska Health Information Initiative, launched in 2008 independent of the state as a nonprofit, payer-funded entity focused on providing health data network services for a fee. Its relationship with the state has significantly evolved, becoming a public-private partnership that has formal agreements with the state.

CyncHealth has a 16-member board with representation from government, hospitals, payers, associations, and consumers. The network has an executive committee, a finance committee, a consumer advisory council, a professional association advisory council, a technical committee, and other committees as needed. CyncHealth has a governance agreement with the large department that houses Medicaid and public health, for data that originates from Medicaid claims, contact tracing, syndrome surveillance, social determinants of health, and public health registries. It became the designated state entity in 2009. No legislation was enacted in creating, forming, or managing CyncHealth. Rather, collaboration with the state has forged a business partnership.

### Data Model

CyncHealth has a central data warehouse that allows data to flow among various systems. Although it uses centralized policies to govern the data network, it does not mandate that participants use a specific data-sharing technology. Instead, it hosts and standardizes the data so that all participants can access and view the data across systems.

### Participation Incentives

Nebraska enacted a statute that requires all prescribers and dispensers to check the PDMP before prescribing medications, and CyncHealth is fully integrated with the PDMP database. While regularly accessing the PDMP, providers become aware of the additional patient information in the health data

network and begin to access the system for a broad range of purposes.

### Coverage of High-Priority Needs

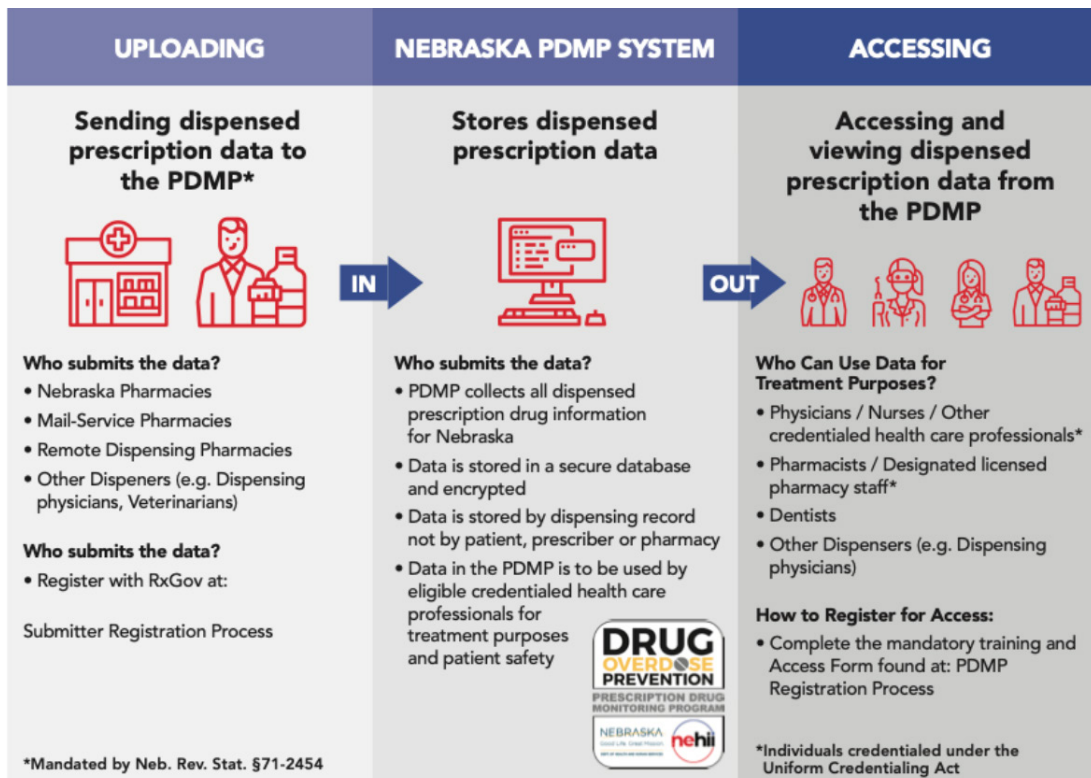
Although use of the CyncHealth data network to share patient records is voluntary, the network has developed solutions that enable its users to fulfill mandatory requirements.

► **Meeting PDMP requirements.** Nebraska launched a PDMP in 2017 that is fully integrated with CyncHealth. It lets providers query prescriptions dispensed from pharmacies and other dispensaries. The Nebraska PDMP is unique in that it holds all prescribed medications, not just opioid drugs, which gives prescribers and dispensers the ability to view a patient’s full medication history. The PDMP holds prescription information for all residents with a Nebraska zip code, even if the patient traveled and fulfilled a prescription outside of the state, so

long as the patient used a major national pharmacy. In 2019 the state established a PDMP state committee that provides oversight of the PDMP and its activities with CyncHealth. Figure 1 explains how data flow in the PDMP.

- **Reducing administrative burden.** By virtue of being a health data network with broad participation, CyncHealth enables organizations to connect once to CyncHealth and reduce the number of systems they would otherwise need to integrate with, such as public health agencies to satisfy public health reporting requirements or to payers for quality improvement programs.
- **Avoiding duplication of health services.** By providing a complete patient record, CyncHealth is able to help providers and patients avoid unnecessary tests or procedures otherwise caused by missing patient records.

Figure 1. Nebraska Prescription Drug Monitoring Program



Source: “Nebraska Prescription Drug Monitoring Program,” CyncHealth, n.d.

► *Addressing social determinants of health.*

CyncHealth matches patients with data from the Supplemental Nutrition Assistance Program, Temporary Assistance for Needy Families, Child and Family Services, and other human service agencies. It provides these agencies demographic data that assist with care coordination. CyncHealth has a platform that enables social care organizations to send and receive electronic referrals, helping them address people's social needs and improve health care outcomes across communities. CyncHealth is expanding its SDoH platform to several additional states: Iowa, Kansas, Minnesota, North Dakota, and South Dakota.

► *Responding to the COVID-19 pandemic.*

CyncHealth is the conduit for receiving ADT information, lab results, and COVID-19 surveillance data from inpatient and ambulatory settings. CyncHealth has connected facilities (at no cost) to help them report COVID-19 data to public health agencies. It has also created dashboards to provide COVID-19 data to clinicians and state agencies, as well as a real-time report about bed utilization based on ADT feeds to assist with patient transfers.

### The Future of Data Exchange in Nebraska

CyncHealth holds fast to its mission, providing better care and improved outcomes. The organization credits its success to not simply focusing on technology and regulations, but to building relationships, to ensuring the connections it provides are handled correctly, and to delivering data that are actionable in a clinical context.

CyncHealth also believes that its PDMP is a model for many states, particularly its inclusion of all prescription drugs. Over time, the organization hopes to provide additional value for participants and patients by leveraging the combination drug and clinical information for better outcomes and lower costs.

In addition, CyncHealth believes that regions within and across states need to forge partnerships. Patients in rural areas go to cities for care. Without statewide

data exchange infrastructure, rural patient data, for example, sits isolated in systems that do not communicate. CyncHealth intends to work to ensure that patient data are portable by networking the entire state ecosystem (including Nebraska's Medicaid agency, payers, hospitals, clinics, and skilled nursing facilities) and expanding beyond state boundaries.

## New York

The Statewide Health Information Network for New York (SHIN-NY) is a statewide hybrid health data network with a central hub that acts as a data highway without storing data.<sup>31</sup>

### Originating Authority and Oversight

New York has a long history of supporting health information exchange. The early days supported regional health information exchange using federal grants to approximately 12 regional exchanges. In 2010, a statute directed the Department of Health (DOH) to promulgate regulations that would provide for the creation of SHIN-NY to coordinate data sharing across the qualified entities (QEs), establish the overarching governance and rules of the road, and provide for a central hub to support these activities. The DOH relies on the New York eHealth Collaborative (NYeC, pronounced "nice") to lead the advancement of SHIN-NY. The system allows participating health care professionals, with patient consent, to quickly access electronic health information and securely exchange data statewide. Similar to the other networks examined for this report, the system benefits from a high degree of support from state health agencies and the governor's office.

The QEs are certified by the DOH, and NYeC contracts with QEs for the core statewide services and sets their performance standards. The QEs receive data from 100% of hospitals in the region. Approximately 80% of ambulatory and behavioral health providers are connected to SHIN-NY, with more than 60% contributing data.<sup>32</sup>

## Data Model

SHIN-NY is a network-of-networks system that connects regional networks known as qualified entities (QEs). At its core, it provides a master patient index and helps identify the availability of patient records across all QEs. Each QE has its own platform and vendor, and enrolls participants within its region, including hospitals, clinics, home health care agencies, payers, and ambulatory practices. Participants can access and exchange electronic health information with others in their region. When a user of one QE queries the system, a message is sent to the SHIN-NY hub to see if that patient has records in any other QEs, in which case it sends the data to the requester. For use cases such as ADT alerts, the SHIN-NY hub points to which other QEs should be notified.

Health care data reside in the QEs, not in SHIN-NY. In that respect, SHIN-NY can be thought of as delivering mail but not opening it. It notifies a QE that it has mail to open in the form of a query. Even so, through collaboration with NYeC and the QEs, SHIN-NY is able to provide statewide data for strategic state initiatives.

## Participation Incentives

New York's regulatory framework requires that certain providers with certified EHRs connect and exchange data with QEs and SHIN-NY. Additionally, the state has maintained a Data Exchange Incentive Program (DEIP), managed by NYeC, that helps to offset providers' costs of connecting to the network.

## Coverage of High-Priority Needs

Core use cases, such as health records, ADTs, results delivery, and other alerts, are provided to all users. Value-added services that users pay for include alerts that contain additional customized information, analytics used for predictive modeling, data about medications sold but not picked up, and more.

SHIN-NY has assisted with the COVID-19 response by partnering with the state to manage lab results and send alerts to providers for patients who have positive results. SHIN-NY also sends data extracts to public health agencies to help track patients who were admitted to or transferred to and from hospitals.

## The Future of Data Exchange in New York

In the future, New York will focus on efforts to access behavioral health and social determinants of health data, which traditional systems generally do not include but which are critical to whole-person health.

## A Framework for Success

Research conducted for this report suggests three features are critical to implementing statewide health data networks successfully. Together they offer a framework that can help policymakers navigate the most important issues as they consider implementing a statewide health data network in California.

### The State Takes a Strong Leadership Role

Experts generally agree that successful states established strong leadership to set policies and priorities, use rulemaking authority to encourage participation, and access federal funding to advance the statewide health data network. Strong state leadership means that a high-level official within the state government is appointed to oversee the exchange efforts. Each of the four states profiled in this report has a director of an Office of Health Information Exchange, operating at a high level within a state agency such as the Department of Health and Human Services, with rulemaking and enforcement authority over the program.

### A Multistakeholder Board Provides Transparency and Accountability

All the successful states profiled in this report created a multistakeholder board to provide oversight, help set priorities, and craft policies for the statewide health data network. These boards have representatives from the public, nonprofit, and private sectors, and participation from the state. Many of the statewide health data networks also have a complementary set of committees that advise on technology and implementation. These diverse groups worked incrementally to build trust across organizations with different perspectives and establish minimum standards for exchange.



They started by taking small steps, which eventually became big steps, and focused on execution and delivering as promised.

## The Networks Tap Public and Private Funding

Each of the statewide health data networks profiled in this report relied heavily on federal funding, and they still require public funding at the federal and state level to be sustainable. In general, these states receive 50% to 80% of their funding from federal and state sources. These networks are often designed with authority and accountability resting within the state Medicaid agency, which generally falls under the state's Department of Health and Human Services so that they are eligible to receive CMS federal funding. The availability of COVID-19 relief funds presents another opportunity to access federal funds to advance a statewide health data network. As discussed earlier in this paper, networks built by MCOs or large hospital systems generally cannot tap either direct CMS federal funding or most of the CRF funding, and must instead seek other ways to recover or absorb the costs. (See Appendix B for a detailed discussion on leveraging federal funding for statewide health data networks.)

Many states, including the four states profiled in this paper, impose participation fees and charge for robust services such as data analytics. Some states seek outside grants for specific projects, such as care management, to provide additional funding, and others establish provider or payer incentive pools to drive up utilization and revenues. Requiring providers to participate and offering financial incentives promotes financial sustainability and yields higher engagement among users.

## How Health Data Networks Can Help Fight COVID-19

An effective COVID-19 response requires mature statewide data exchange. To accomplish this, the state needs to ensure (and mandate if necessary) that some data flow through health data networks to and from public health systems, and that public health systems and organizations have the infrastructure and upgraded capabilities necessary to participate.

A statewide health data network can provide mechanisms that allow public health agencies and providers to exchange COVID-19 testing, tracing, and vaccine efforts. Examples of how the four states used their statewide network for successful COVID-19 response include:

- ▶ Partnering with the state to manage lab results and send alerts to providers for patients who have received positive results, as well as sending data extracts to public health agencies to help track patients who were admitted, discharged, or transferred to and from hospitals.
- ▶ Identifying, tracing, and tracking COVID-19 vaccinations in a statewide network that does not routinely store data, which avoids health plan concerns that they do not have complete control over their data, to realize the better public good.
- ▶ Feeding COVID-19 test results into the statewide network, which then can run reports by zip code and feed the results to public health agencies for tracing and tracking.
- ▶ Making inventory reports available that show levels of personal protective equipment.
- ▶ Using a network's master patient index report about positive COVID-19 results to uncover disparities among groups, races, ethnicities, and income levels.
- ▶ Using the network's demographic capabilities to meet the new Coronavirus Relief Fund requirements that states target certain populations and geographic areas for assistance and vaccination.



# What California Can Learn from Other States

Leaders from the states interviewed for this report did not see California's large size and wide variety of health data networks as insurmountable issues. Interviewees see the question as not if California will act, but how California will create a health data network in ways that benefit everyone.

Based on lessons learned from implementing other statewide health data networks, interviewees offered both high-level and specific insights. All agreed that California should consider the following options:

- ▶ Establish a leadership role for state government in law. Keep the statute to top-tier policy issues such as governance, participation by providers and payers, consumer access to the data, data privacy, and financing. The statute should describe the state role and the role of private and public partners with regard to administration and operation of the statewide health data network.
- ▶ Build in a mechanism for broad stakeholder participation, oversight, and accountability.
- ▶ Recognize that use cases must drive the expansion of health information exchange over time. Incrementally implement solutions, starting with a problem most people believe should be addressed.
  - ▶ Move from planning to action by identifying a unified agenda and priorities among private and public entities and working to apply that agenda to the execution of a state framework.
  - ▶ Identify outcomes or features needed for a viable statewide network rather than mandate specific technologies and standards. California has the opportunity to include features that target the need for improved data sharing, including behavioral health and social determinants of health.
- ▶ Provide incentive “carrots” for participation in the networks and use enforcement “sticks” for entities that do not fully participate. Consider participating in or organizing payer pools where only users of the statewide network share proceeds, and charging participation fees and separate value-added service fees to promote greater participation and sustainability.
- ▶ Take full advantage of federal funding, including funds from the Coronavirus Aid, Relief, and Economic Security (CARES) Act and the Coronavirus Relief Fund (CRF), for investment in data exchange capabilities and infrastructure.
  - ▶ Use the forthcoming update of the State Medicaid Health Plan (SMHP), required under the HITECH Act and due to be submitted to CMS no later than March 2022, to take advantage of 90% federal funding to help inform planning processes for a statewide health data network.
- ▶ Recognize that the state needs to have a statewide system, called a master patient index, to associate all the health records for a patient, regardless of how individual systems identify patients, and make that a requirement of the statewide health data network.

While no consensus emerged among those interviewed about whether California should pursue a centralized model or operate as a hybrid network of networks, some did note that if California decided on a hybrid model, the hub could operate as a pass-through data highway and not a permanent data repository to avoid health plan and MCO concerns about not having complete control over their data.

## Evolution of the Michigan Data Exchange

**Starting with existing networks.** The data architecture of each of the statewide health data networks profiled in this report followed from, at least in part, what existed when that network formed. In Michigan, where multiple HIOs existed when the network was created, stakeholders recognized that many organizations had already invested in health information exchange and that an entirely new centralized network ran counter to their interests. While those HIOs were allowed to sustain themselves, Michigan has seen significant consolidation of its networks since the end of ONC funding in 2014, enabling those left standing to benefit from more favorable economies of scale.

**Starting small and gaining trust.** Michigan started to expand its services by implementing ADT alerts. That implementation got people used to working together and built trust, which in turn enabled Michigan to use its health information exchange capabilities to enhance its response to COVID-19. Michigan does not routinely store data in its systems. However, data for use cases such as COVID-19 identification, contact tracing, and vaccinations required data be held for a period of time. Network participants were comfortable with their data being stored for a specific reason and time period during a public health emergency. As relationships allow, use case solutions and processes continue to mature.

## The Future of Health Information Exchange

The state leaders interviewed provided valuable insights about health information exchange over the next five years:

- ▶ There will be further consolidation of HIOs, particularly given that funding will be subject to further requirements for expanded data exchange and additional services that could be costly for the HIOs to build and maintain.
- ▶ Now that federal rules mandate that EHRs and HIOs must be able to communicate with each other (interoperability), the regulations are here to stay and will be the way to further improve health outcomes.
- ▶ Attempts to integrate behavioral health data and social health data with clinical information in networks will continue to improve as stakeholders resolve security, privacy, and patient consent issues.
- ▶ States will continue to access enhanced federal funding from federal programs and CMS funding or Medicaid projects, including health data networks. Yet there will be challenges, such as allocating costs between Medicaid and non-Medicaid populations for CMS funding.

The way forward will not be without its challenges. Countering these headwinds that limit data sharing will be the work of leaders at every level.

## Appendix A. Glossary of Terms

**All-payer claims database (APCD).** A repository of health care claims administered by an agency and established by law that requires all payers to submit claims data, including demographic and health care codes that identify the services and time billed for each claim.

**Application programming interface (API).** Computer code that enables data transmission between one software product and another. In this report, the term refers to the system that enables patients to easily access their health records electronically using a device of their choosing.

**Data application.** A class of software designed to enable access to information electronically, such as a web browser.

**Electronic health records (EHRs).** Computer devices and systems that providers use to record demographic and clinical patient data such as blood pressure, known health conditions, treatments, immunizations, and sometimes information like homelessness or food insecurity, also known as social determinants of health.

**Health information exchange (HIE).** A technology-driven method that permits health care providers to securely send, receive, and share patient medical records and data electronically. The exchange stores patient health records submitted electronically by health care providers and others via EHRs in a data warehouse, or acts as a data highway that data flow through. The result is that health care professionals can access and share patient data.

**Health information organization (HIO).** Entities that facilitate the exchange of patient health information among the enterprises composing a health care delivery system. They can be community-based and nonprofit, and are known in California as regional HIOs.

**Health information network (HIN).** A network of HIOs or other data networks connected by an entity that coordinates data sharing among them.

**Interoperability.** The ability of different electronic systems to communicate and share information with each other. To achieve interoperability, EHRs and health data networks need common standards or technology that can translate information so other systems can use it.

**Use case.** The resolution of a particular health care scenario by using health information data and exchange.

## Appendix B. Federal Funding Opportunities for California

Ultimately, to be successful, statewide health data networks need to have sustainable funding. A mix of federal, state, and participation fees along with high participation has provided the four statewide networks profiled in this report with a sustainable business model. It is critically important for California to act now to tap into several sources of federal funding to support health information exchange.

Currently, other than COVID-19 relief funding, most sources of federal funding require a state “match,” and none of them will cover the complete cost of statewide health network development. Medicaid is the largest source of federal funding available to states for health data network development and operations. Table B1 identifies the source and percentage of federal funds available for Medicaid-related projects.

**Table B1. Sources of Federal Funds**

|  | FEDERAL MATCH | FEDERAL FUNDING AVAILABLE | STATE-BASED ENTITY  | PURPOSE   |
|--|---------------|---------------------------|---|---|
| <b>CMS/Medicaid</b>                        |               |                           |   |   |
| <b>HITECH Act</b>                          | 90%           | No set amount*            | State Medicaid Agency   | To administer the Promoting Interoperability Program. Funding available only for close-out activities and 5-year State Medicaid Health Plan (SMHP).   |
| <b>MES Projects</b>                        | 90%           | No set amount             | State Medicaid Agency   | For the design, development, and implementation (DDI) of new Medicaid enterprise systems (MES) projects.  |
| <b>MES Maintenance and Operations</b>      | 75%           | No set amount             | State Medicaid Agency   | For the ongoing maintenance of MES.   |
| <b>Medicaid Program Administration</b>     | 50%           | No set amount             | State Medicaid Agency   | General administrative funding.   |
| <b>Coronavirus Relief Fund<sup>†</sup></b> |               |                           |   |   |
| <b>ONC for HIE</b>                         | 100%          | \$62.4M                   | State Medicaid Agency   | Operating budget and for the development and advancement of interoperable HIT (details TBD).  |
| <b>Public Health</b>                       | 100%          | \$73B                     | Various state departments, under HHS, including public health and behavioral health | For COVID-19 response, including vaccine distribution, testing, and contact tracing. Also for mental health and substance use services and support. Funds may be used to develop specific data functionality to meet COVID-19 response. |
| <b>Broadband and Telehealth</b>            | 100%          | \$7B                      | Broadband providers, provider organizations   | To improve broadband coverage.  |

\*Main funding ends September 2021; SMHP funding ends March 2022.

<sup>†</sup>Individual components end late 2021 through early 2023.

## Centers for Medicare & Medicaid Services Funding

The level of CMS funding available for state Medicaid programs is based on the annual CMS appropriations in the federal budget. Generally, there is no set amount of funding for each CMS program per se. This section will describe the percentage of CMS funding applied to the cost of Medicaid projects, including statewide health data network projects that meet federal requirements. For example, projects that qualify for 90% federal funding can expect CMS to pay 90% of the total cost, with the state paying the 10% “match.”

**Conditions.** There are two major CMS requirements that generally apply to get federal funding:

- ▶ The Medicaid agency must maintain accountability and direction of the project and program
- ▶ The federal funding can be used only to pay for the portion of the project that benefits the Medicaid population (cost allocation)

### 90% Federal Funding for the Health Information Technology for Economic and Clinical Health (HITECH) Act,<sup>33</sup> Program Administration of the Promoting Interoperability Program

**Percentage.** This 90% federal funding is available for state Medicaid agencies to administer the Promoting Interoperability Program. (The 90% federal funding ends September 30, 2021, except for close-out activities and a five-year HIT plan due in 2022.)

**Funding example.** At this late stage, the 90% federal funding is generally available only for Medicaid program close-out activities. However, a significant close-out activity is the development and submission of an updated five-year State Medicaid Health Plan (SMHP), which consists of identifying all current health information activities and systems in the state, including claims, clinical records, Medicaid enrollment, and claims system, and private and public health-related systems and network. The updated SMHP is eligible for the 90% federal funding through March 2022 when the SMHP must be submitted to CMS.

- ▶ California could leverage the 90% federal funding to conduct a stakeholder process that inventories the myriad health data systems and identifies where the state wants to be in five years, the gaps from the as-is to the “to-be” vision, and what actions need to be taken to fill the gaps.

### 90% Federal Funding for Medicaid Enterprise Systems (MES) Projects<sup>34</sup>

**Percentage.** The 90% federal funding is available to new Medicaid design, development, and implementation (DDI) projects for claims, enrollment, prescription drug management, HIEs, public health, and related system projects.

#### Example projects:

- ▶ Sending alerts to Medicaid providers for care manager follow-up when a Medicaid member visits the emergency department.
- ▶ Master provider index system: A tool that care managers or patients check to locate Medicaid providers in their area, and to find providers available to see new Medicaid patients.
- ▶ Systems that integrate a PDMP registry with a statewide health data network to enable prescribers and dispensers to check before issuing opioid drugs.

**Duration.** The availability of the 90% federal funding is ongoing.

### 75% Federal Funding for Maintenance and Operation of Medicaid Enterprise Systems (MES)

**Percentage.** This 75% federal match is to maintain and operate “fully functional and certified” DHHS systems.

**Duration.** The 75% federal funding is ongoing and does not have an end date.

Projects or systems that are fully functional and certified by CMS move from 90% federal MES funding to 75% federal funding. Fully functional is defined as

the “go live” date, plus an additional approximately 90-day stabilization period and then at least six months of operations. The certification process consists of the state working with CMS to determine the cost of the project that benefits the Medicaid population (cost allocation) and to develop outcomes and measures that the state reports on to demonstrate progress (e.g., the percentage of prescribers and dispensers checking the prescription drug registry system before drugs are prescribed or dispensed, as confirmed by a quarterly audit).

### 50% Federal Funding for Medicaid Program Administration

**Percentage.** The 50% federal match is for general administrative functions performed by the Medicaid agency, such as Medicaid staff assisting health care providers to enroll in order to serve Medicaid patients, or auditing for fraud, waste, and abuse.

**Duration.** Administrative funding is ongoing and does not have an end date.

**Note.** The 50% administrative match is to administer the Medicaid program. It is different than the Federal Medical Assistance Percentage (FMAP), the percentage that the federal government pays for Medicaid provider services. For example, a Medicaid provider sees a Medicaid patient for an ankle sprain and bills Medicaid the allowed \$100 rate. The federal government pays its share, say \$50, and the state pays the other \$50. The FMAP is state-specific, ranging from 50% to 77%, with California’s FMAP being 50%.

## Federal Funds Under the CARES Act and Coronavirus Relief Fund

**Percentage.** 100% federal funding

**Duration.** The March 2020 Coronavirus Aid, Relief, and Economic Security (CARES) Act provided significant emergency funding for COVID-19 response through December 2020.<sup>35</sup> The Coronavirus Relief Fund (CRF), which was part of the December 2020 annual federal budget law<sup>36</sup> extended CARES Act projects through December 31, 2021. It also appropriated new funding to be used by December 2021 through early 2023, depending on the program.

The CRF makes specific appropriations for states to secure funding for health data networks and data exchange. Some of the funding will come as a “pass-through” to states under block grants or other means, while other funding may require states to make grant or other applications. (Some funding allows for non-government entities to apply for grants.) Below is a brief high-level overview of CRF funding relevant to health data networks and how they can improve data sharing and health outcomes.

Some of the funds available are targeted to support vulnerable or rural populations. Having a statewide health data network will allow states to better serve these populations and be in compliance with funding requirements. The four states profiled in this report will be able to provide the data to meet these requirements, which cannot be accomplished without a statewide health data network system.

### Office of National Coordinator for Health Information Exchange

The Office of the National Coordinator for HIE (ONC),<sup>37</sup> a division of CMS, leads the effort to have all EHRs able to share data with other EHRs (interoperability), which generally happens at the HIE (health data network) level. The CRF appropriates \$62,367,000 for agency operations, which includes an unspecified amount for grants, contracts, and cooperative agreements for the development and advancement of interoperable



health information technology. (Note: As of the date of publication of this report, the particulars of the grant process are still being developed.)

- ▶ For states that want to get grants for statewide health data network projects, they will likely have to apply for the funding (through the Medicaid agency) and meet the CMS condition that the Medicaid agency retain accountability and direction over the health data network.

## Public Health

Although the CRF makes dollars available to private and nonprofit payers and health care facilities and systems, the majority of the funding is either appropriated directly to state, local, and tribal governments or appropriated to public agencies to administer the grants and projects. Some of these funds are available to state DHHS agencies, including projects that develop specific functionality in a statewide health data network (provided it meets the CMS conditions). The CRF appropriates \$73 billion to the US Department of Health and Human Services to support public health, including:

- ▶ \$8.75 billion to the Centers for Disease Control and Prevention (CDC) to support federal, state, local, territorial, and tribal public health agencies to distribute, administer, monitor, and track coronavirus vaccination to ensure broad-based distribution, access, and vaccine coverage. It includes \$300 million for a targeted effort to distribute and administer vaccines to high-risk and underserved populations, including racial and ethnic minority populations and rural communities.
- ▶ \$25.4 billion to the Public Health and Social Services Emergency Fund to support testing and contact tracing, to effectively monitor and suppress COVID-19. This fund includes \$2.5 billion for a targeted effort to improve testing capabilities and contact tracing in high-risk and underserved populations, including racial and ethnic minority populations and rural communities.

- ▶ \$4.25 billion for the Substance Abuse and Mental Health Services Administration to provide increased mental health and substance abuse services and support, which includes specified dollar amounts or percentages for tribal and state projects and clinics. A certain percentage must be distributed to states with the highest mortality rates related to opioid use disorders, and a certain percentage to all states for treatment (including medication), referral, and behavioral health services for those in treatment programs, support, and medical screening.
  - ▶ The \$4.25 billion for substance use is particularly important to states, as there are percentage and dollar appropriations specifically earmarked for state grants, including at least \$4 million for each state for substance use disorder treatment. The Medicaid agencies for the four states profiled in this paper will be able to apply for grants, for example, that will enable their statewide health data network to develop the provider index API that will be used to identify available treatment providers and programs.

## Broadband and Telehealth

Reliable access to broadband is critical for providers and patients to have access to connected data systems that can share data. The Coronavirus Relief Fund has made available \$7 billion to expand broadband access for students, families, and unemployed workers. While this funding typically flows through broadband providers or individual provider organizations, state leadership could help coordinate these efforts to meet specific state goals. These funds include:

- ▶ A new \$3.2 billion Emergency Broadband Benefit that will provide \$50 per month for broadband for low-income families
- ▶ \$300 million for rural broadband
- ▶ \$250 million for expanding the Federal Communications Commission's telehealth program, which pays a portion of a health care provider's broadband and telehealth equipment

- ▶ \$65 million to improve mapping that shows where broadband is and is not, to better target areas where broadband investment is needed the most

These federal funds can be used to help pay for upgrading internet services. The lack of reliable broadband (high-speed internet) as a barrier to expanding HIE. Broadband is needed to electronically provide telehealth services like Zoom visits between providers and patients, remote patient monitoring for vital signs, and transmitting lifesaving medical scans electronically from accident sites to hospitals. None of these activities can be done via telephone. Studies show that access to telemedicine results in improved health care and patient safety by reducing Medicaid transportation costs as well as lost education and work time; avoiding expensive emergency room visits; and improving health care in rural areas with provider shortages, especially in the behavioral health fields.<sup>38</sup> Broadband is critical in enabling access to telemedicine and electronic exchange of data, which is especially important during the COVID-19 pandemic. Making funding available for broadband expansion also contributes to the number and type of health care providers who implement EHRs and connect to a health data network, both of which require internet services and have been identified by California stakeholders as an activity the state should engage in.

The four states highlighted in this paper, which have statewide health data networks, gained significant benefits for COVID-19 response activities. For COVID-19 response, broadband is needed to trace, track, and identify specific populations; administer vaccines; and report to public health agencies. Statewide health data networks greatly facilitate gathering and reporting information to public health agencies by segregating the aggregated data flowing into the network into categories such as age, race, rural community, and ethnic minority population to better target COVID-19 response to high-risk areas and populations. A statewide health data network can report information on a global and individual patient level for the entire state.

## Appendix C. Interviewees

### **California Association of Health Information Exchange**

Robert “Rim” Cothren, principal, Cuning Plan;  
executive director, CAHIE

### **California Department of Health Care Services**

Linette Scott, deputy director and chief data officer

### **California Public Employees Retirement System**

Heather Readhead, MD, MPH,  
medical director of clinical programs

### **Chesapeake Regional Information System for our Patients**

David Horrocks, president and CEO

### **CyncHealth**

Jaime Bland, DNP, RN-BC, CEO

### **Georgia Health Information Exchange Network**

Pam Matthews, executive operations officer

### **Kaiser Permanente**

Jamie Ferguson, vice president,  
Health Information Technology  
Walter G. Suarez, MD, MPH, executive director,  
Health IT Strategy and Policy  
Teresa R. Stark, director, state government  
relations for Kaiser Permanente

### **Manifest MedEx**

Claudia Williams, CEO  
Paul Norton, director, Policy

### **Michigan Health Information Network**

Tim Pletcher, executive director

### **New York eHealth Collaborative**

Valerie Grey, CEO  
Nathan Donnelly, senior vice president,  
Policy and Analysis

### **Oregon Health Authority**

Susan Otter, director and state coordinator for  
Health Information Technology  
Luke Glowasky, business analyst

## Endnotes

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2. "What Is HIE?," healthit.gov, last reviewed July 24, 2020.
3. "What Is HIE?," healthit.gov.
4. Jim Maxwell et al., *National Approaches to Whole-Person Care in the Safety Net* (PDF), John Snow Inc., n.d.
5. "Policies and Technology for Interoperability and Burden Reduction," Centers for Medicare & Medicaid Services (CMS), last modified February 5, 2021.
6. "Policies and Technology," CMS.
7. Cindy Mann (director, CMS) to all state Medicaid directors, *SMD letter 11-004* (PDF), May 18, 2011; and "OMB Circular A-87 Revised," obamawhitehouse.archive.gov, last revised May 10, 2004.
8. *86 Fed. Reg. 10* (Jan. 15, 2021) (PDF); and *Rules Committee Print 116-68: Text of the House Amendment to the Senate Amendment to H.R. 133* (PDF), US House of Representatives, December 21, 2020.
9. Details on each state's statewide health data network can be found in the section "Four States with Robust Statewide Health Data Networks."
10. For more information on these levers and how they're applied in several states, see CHCF's *Expanding Payer and Provider Participation in Data Exchange*, which includes additional detail on Maryland and Michigan.
11. Christopher Jason, "Information Blocking by EHR Vendors, Health Systems Still Prevalent," *EHR Intelligence*, January 11, 2021.
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13. Prashila Dullabh et al., *Evaluation of the State HIE Cooperative Agreement Program: Final Report* (PDF), NORC, March 2016.
14. Cindy Mann, state Medicaid director letter.
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16. *86 Fed. Reg. 10*; and *Rules Committee Print 116-86*.
17. Kate Monica, "Social Determinants of Health Data Deemed Most Difficult to Share," *EHR Intelligence*, May 20, 2019.
18. "What Are the Benefits of Health Information Exchange?," healthit.gov, last reviewed January 8, 2019.
19. "Health Information Exchange (HIE)," Univ. of South Florida, last updated November 2, 2020.
20. *Index for Excerpts from the American Recovery and Reinvestment Act of 2009 (ARRA)* (PDF), healthit.gov, last reviewed February 19, 2009.
21. *Index for Excerpts*, healthit.gov.
22. "Helpful Information About Health Information Exchanges (HIE's)," Lyniate, n.d.; and Strategic Health Information Exchange Collaborative, n.d.
23. "Interoperability and Patient Access Fact Sheet," CMS, March 9, 2020.
24. Monica, "Social Determinants."
25. "Social Determinants."
26. Leaders from two additional states were briefly interviewed because of the relevance of their governance models to California. Oregon employs a statewide network-of-networks approach that features extensive stakeholder involvement, including an oversight council, specialized committees, health industry group, a health policy board, and a health information exchange community and organizational panel. Georgia operates a network of networks with four regional systems and five large health care systems that feed data into the network. The Georgia Health Information Network (GaHIN) has a unique business model in which members contract with the health data network vendor and sign a subscription agreement with GaHIN that provides oversight of the relationship.
27. "Health IT Data Summaries," healthit.gov, n.d.
28. MiHIN, n.d.
29. CRISP, n.d.
30. CyncHealth, n.d.
31. NYeC, n.d.
32. New York law requires patient consent for data exchange, so the data exist in the QEs but are not generally accessible by others in the network until patients consent to having their data exchanged.
33. Cindy Mann, state Medicaid director letter.
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