

## Data Exchange Framework Governance

### Section Draft

May 12, 2022

## I. Why Governance Is Needed

### **Relevant AB133 Provisions**

Assess governance structures to help guide policy decisions and general oversight.  
[§130290(c)(3)(J)]

California currently lacks a single governing body to develop, implement, and oversee policies that will advance the meaningful exchange and use of health and human services data throughout the state. Instead, health and human services data exchange and use is governed by an array of state and local government agencies and departments as well as other public and private stakeholders. The governance approaches and policies of these many actors may align in some instances but can also be conflicting, with implications described in [AB133](#):

*“While parts of California’s health care system rely on coordinated, interoperable electronic systems, other parts rely on decentralized, manual, and siloed systems of clinical and administrative data exchange that is voluntary in many situations. This voluntary patchwork imposes burdens on providers and patients, limits the health care ecosystem from making material advances in equity and quality, and functionally inhibits patient access to personalized, longitudinal health records. Further, a lack of clear policies and requirements to share data between payers, providers, hospitals, and public health systems is a significant hindrance to addressing public health crises, as demonstrated by challenges inherent to the COVID-19 pandemic.”*

Other governance models in California and in other states provide insights into how California could establish Data Exchange Framework Governance. States with more robust health and human service data exchange governance models have the following characteristics:<sup>1,2,3,4</sup>

<sup>1</sup> Sandeep Kapoor, JoAnne Hawkins, and Dawn R. Gallagher, “Designing a Statewide Health Data Network: What California Can Learn from Other States” (California Health Care Foundation, March 2021), <https://www.chcf.org/wp-content/uploads/2021/02/DesigningStatewideHealthDataNetworkCalifornia.pdf>.

<sup>2</sup> “Expanding Payer and Provider Participation in Data Exchange: Options for California” (California Health Care Foundation, November 2019), <https://www.chcf.org/wp-content/uploads/2019/11/ExpandingPayerProviderParticipationDataExchange.pdf>.

<sup>3</sup> Jonah Frohlich, Eric Barholet, and Jonathan DiBello, “Why California Needs Better Data Exchange: Challenges, Impacts, and Policy Options for a 21st Century Health System” (California Health Care Foundation, March 2021), <https://www.chcf.org/wp-content/uploads/2021/02/WhyCaliforniaNeedsBetterDataExchange.pdf>.

<sup>4</sup> Karen Ostrowski, Rachel Goldberg, and Mark Elson, “Governance Structures for Statewide Data Exchange in California,” Data Exchange Explainer Series (California Health Care Foundation, April 2022), <https://www.chcf.org/wp-content/uploads/2022/03/DataExchangeExplainerGovernanceStructures.pdf>.

- **The State Takes a Strong Leadership Role:** States that have been successful typically have a high-level official in a health and human services agency who can use rulemaking authority and access federal funding to advance statewide health and human service data exchange.
- **Multi-Stakeholder Committees Provide Transparency and Accountability:** Successful states have multi-stakeholder committee(s) to help provide oversight, set priorities, and craft policies for statewide health and human service data exchange.

Governance Models in California and Other States <sup>5</sup>
<ul style="list-style-type: none"> <li>• <b>California Emergency Medical Services Authority (CalEMSA)</b> <ul style="list-style-type: none"> <li>○ Chapter 1260, Section 1799 of the Health and Safety Code created the commission, effective January 1, 2009, within the California Health and Human Services Agency (CalHHS)</li> <li>○ The commission was defined as a 19-member stakeholder board</li> <li>○ Subsequent bylaws established duties, responsibilities, and appeals functions of the board</li> </ul> </li> <li>• <b>Covered California</b> <ul style="list-style-type: none"> <li>○ AB1602 and SB900 established Covered California in September 2010</li> <li>○ Statute established a new independent public entity governed by a five-member executive board</li> <li>○ Statute specified powers and duties of the new entity and the board governing the exchange (including adopting regulations)</li> </ul> </li> <li>• <b>Examples of HIE Governance in Other States: NY, MD, and MI</b> <ul style="list-style-type: none"> <li>○ Statute granted the authority for a policy board to be housed within a state entity (NY and MD) or the creation of an independent commission to work with state government (MI)</li> <li>○ The state health department retains granted rulemaking authority in all three states</li> <li>○ All three states heavily leverage federal funding through departments of health (Medicaid and Health Information Technology for Economic and Clinical Health [HITECH] Act) to support and expand health information exchange (HIE) capabilities, and leverage health department rolls to align HIE participation incentives</li> <li>○ All three states have created strong leadership positions within state government to advance HIE priorities</li> </ul> </li> </ul>

Formalized HIE governance in California will help drive and oversee the successful implementation and ongoing refinement of the Data Exchange Framework Policies and Procedures, programs, and priorities. This document describes the Data Exchange

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<sup>5</sup> Ibid.

Framework Governance, including its purpose and goals, contractual framework, functions, and model structure.

## II. Purpose and Goals of Data Exchange Framework Governance Structure

The goals of CalHHS Data Exchange Framework Governance are to:

1. Oversee the Data Exchange Framework, which includes development, implementation, refinement, and ongoing maintenance of the state's Data Sharing Agreement and common set of Policies and Procedures, requirements, and guidelines that will govern the exchange of health information among health care entities and government agencies.
2. Adopt and advance Data Exchange Framework Guiding Principles.
3. Create opportunities for stakeholders and the public to have open access to and engage and offer input into governance policy and procedure development, decision-making, oversight, and monitoring processes that support adoption of the Data Exchange Framework and the Data Sharing Agreement, while ensuring security, privacy, and other protections.
4. Provide a forum for the state to consider, respond to, and support adaptation of state laws, regulations, policies, and priorities as the health and human services environment and the needs of Californians change over time.
5. Encourage collaboration among stakeholders serving diverse functions across the California health and human services industry.
6. Identify, prioritize, and address Policies and Procedures, programs, guidelines, and investments needed to support implementation of the Data Exchange Framework and the Data Sharing Agreement.

## III. Governance Legal and Contractual Framework

Data Exchange Framework Governance decision-making authority will rest with the California Health and Human Services Agency, supported by CalHHS' Center for Data Insights and Innovation (CDII) and an HIE Policy Board.<sup>6</sup> CDII will oversee initial implementation of the Data Sharing Agreement and ongoing development and maintenance of its Policies and Procedures and requirements for entities subject to AB133's data sharing mandate. The HIE Policy Board should be established through legislation and, once established, will assume responsibility for a specified set of oversight functions.

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<sup>6</sup> The roles of CalHHS/CDII and the HIE Policy Board are described in greater detail in *Section V. Governance Model Structure and Implementation Approach*.

The health and human service entities defined in AB133 will execute the Data Exchange Framework Data Sharing Agreement with CalHHS. Pursuant to the Data Sharing Agreement, these entities will share data with other health and human service entities in California. The Data Sharing Agreement will incorporate Policies and Procedures that Data Sharing Agreement signatories would be required contractually to comply with. In addition to the terms of the Data Sharing Agreement, health and human service entities must also comply with other data sharing Policies and Procedures and requirements, developed via Data Exchange Framework Governance.

## IV. Governance Functions

Data Exchange Framework Governance will encompass 10 core functions.

### 1. Harmonization of State Law with Federal Law

Data Exchange Framework Governance will ensure that the Data Exchange Framework is aligned with federal and state laws, regulations, and policies that govern data exchange. Specifically, it will:

- Facilitate and oversee a process to identify state laws, regulations, policies, procedures, and guidelines that may conflict with federal law that prohibits (or creates ambiguity and uncertainty that stymies) secure data sharing.
- Advance policy proposals to refine rules and policies, and advance proposals to legislative leaders to amend or establish state law as needed.
- Identify challenges regarding federal law and regulations, and develop approaches to engage with federal partners to resolve conflicts or issues (e.g., Health Resources and Services Administration [HRSA] and United States Core Data for Interoperability [USCDI] version 2 data standard conflicts).<sup>7</sup>

### 2. Development of and Modifications to Data Sharing Agreement Policies and Procedures

Data Sharing Agreement Policies and Procedures establish rules and guidance regarding data sharing implementation requirements that will evolve over time. Data Exchange Framework Governance will review and approve necessary or recommended amendments to the Data Sharing Agreement and Policies and Procedures, which may include (but aren't necessarily limited to):

- Evolution of state and federal law and implications for California Data Sharing Agreement Policies and Procedures.
- Reassessment of any thresholds or minimum requirements set forth in the Data Sharing Agreement.

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<sup>7</sup> See *Opportunity #1.4: Recommendations to the Federal Government to Improve Demographic and SDOH Data Collection Nationally* for additional context on this issue.

Data Exchange Framework Governance will also oversee processes that include substantial stakeholder engagement on an ongoing basis to identify and develop new Policies and Procedures. The initial list of Policies and Procedures that will be released on July 1, 2022, include:

- Amendment of the Data Sharing Agreement
- Amendment of Policies and Procedures
- Data Elements to Be Exchanged
- Breach Notification
- Permitted and Required Purposes
- Requirement to Exchange Health Information

### **3. Additional Data Sharing Policies and Procedures and Requirements**

Data Exchange Framework Governance may develop and institute requirements that cover additional topics beyond the Data Sharing Agreement Policies and Procedures released on July 1, 2022. Such topics may include:

- Obligations to cooperate with respect to the Data Exchange Framework;
- Non-discrimination – including restrictions against prohibiting or impeding exchange with other health and human service entities;
- Obligations to provide notification of any adverse security events; and
- Others as defined by CalHHS/CDII and the HIE Policy Board.

### **4. Review of Federal Standards and National Efforts Impacting Data Exchange**

Data Exchange Framework Governance will monitor federal standards and national efforts impacting data exchange and will maintain a dialogue with federal agencies overseeing such initiatives. Specifically, it will:

- Identify gaps and consider opportunities to expand upon federal policy where it falls short or has not been developed.
- Engage with federal agencies regarding updates to federal standards and policies, and advance policy recommendations to federal agencies, including Centers for Medicare & Medicaid Services (CMS), Office of Civil Rights (OCR), Centers for Disease Control (CDC), and others.

### **5. Enforcement of and Monitoring Compliance with Policies and Procedures, Requirements, and Guidelines**

Through engagement with stakeholders and other state agencies, Data Exchange Framework Governance will establish appropriate monitoring and enforcement procedures that avoid duplicating the work of existing state oversight authorities. Specifically, Data Exchange Framework Governance will:

- **Monitor compliance** with Data Sharing Agreement Policies and Procedures, requirements, and guidelines, and with other state policy, and identify and address breaches or non-compliance, potentially through attestations, audits, grievance processes, and other mechanisms.
- **Enforce requirements** by responding to breaches in or non-compliance with Data Sharing Agreement Policies and Procedures, requirements, and guidelines, as well as other state rules, potentially with sanctions and remedies that may include monetary penalties, remediation plans, and/or suspension of participation.
  - Enforcement processes should include a process for appeals.
  - The state will conduct additional stakeholder engagement and release the Data Sharing Agreement and the initial set of Policies and Procedures before establishing formal enforcement processes.

Data Exchange Framework oversight authorities will be aligned among different state agencies, to the extent possible, as different stakeholders subject to AB133 are regulated by different state agencies.

## 6. Oversee Dispute Resolution and Grievance Processes

Data Exchange Framework Governance will establish and oversee processes to address disputes and grievances among impacted parties. Such processes may include:

- Facilitating regular discussion of any widespread issues impacting the Data Exchange Framework and its stakeholders.
- Overseeing dispute resolution and grievance processes set forth in Policies and Procedures, requirements, and guidelines.

## 7. Program Development and Financing

Data Exchange Framework Governance will define programs to advance data exchange in California and will examine which funding sources can be used to best support those initiatives. Specifically, it will:

- Identify areas of need and growth and opportunities to expand HIE, such as:
  - Identifying additional priority exchange activities;
  - Developing HIE use cases to be integrated into programs, Policies and Procedures, requirements, guidelines, and contracting requirements;
  - Considering need for and potential changes to privacy and security laws and regulations in order to inform modification of privacy and security policies and procedures; and
  - Developing social determinants of health (SDOH), demographic, and sexual orientation and gender identity (SOGI) data collection and use incentive programs.

- Establish a framework and parameters for programs to support the adoption and implementation of the Data Exchange Framework, such as:
  - Technical assistance for small/under-resourced providers (e.g., to support organizations' adoption of electronic health records [EHRs]); and
  - Incentive programs across public and private payers aligned with use case priorities and with consistent terms and requirements (e.g., potential EHR and HIE onboarding incentive programs).
- Develop and approve annual strategic plans that evaluate implementation progress and set forth goals, priorities, and budget requests.
- Support activities that enhance interagency and inter-departmental data sharing practices and activities.

## 8. Identification and Qualification of Data Exchange Intermediaries

Data Exchange Framework Governance will identify and qualify data exchange intermediaries with whom health and human service entities can connect to help meet their data sharing obligations under AB 133. Specifically, it will:

- Establish minimum requirements for qualified data exchange intermediaries.
- Identify entities and intermediaries who meet minimum state requirements and can support data exchange.
- Establish, revise, and oversee compliance with requirements intermediaries must meet to qualify, receive state funds, and help Data Exchange Framework participants meet their obligations under the Data Sharing Agreement. Examples include:
  - Form of entity and state of organization (for example, considering how qualifying requirements should address national data exchange intermediaries such as Carequality)
  - Minimum assets and/or services
  - Minimum insurance requirements
  - Attestations to conform with Data Sharing Agreement Policies and Procedures and other state requirements and guidelines

## 9. Communications and Education

Data Exchange Framework Governance will raise awareness and support stakeholder education about the Data Exchange Framework to encourage adoption and use. Specifically, it will:

- Market and promote the Data Exchange Framework to encourage adoption and usage;
- Educate individuals about their rights with respect to data sharing and what the Data Exchange Framework means for them;
- Develop best practices regarding the Data Exchange Framework via informational guidelines;

- Report on participation and new developments; and
- Connect needs and support requests with available resources and tools.

## 10. Coordination with Other Branches of State and Local Government

Data Exchange Framework Governance will work with other branches of state and local government to support implementation of and participation in the Data Exchange Framework. Specifically, it will:

- Develop processes and policies to share data between other CalHHS departments and state agencies.
- Coordinate with licensing agencies to develop Policies and Procedures and support implementation of the Data Exchange Framework – including, for example, updates to provider directory information and provider credentials (e.g., endpoints).
- Develop processes and support inclusion of county and local health, public health, and human services agencies, as part of the Data Exchange Framework, to assist both public and private entities in connecting through uniform standards and policies.

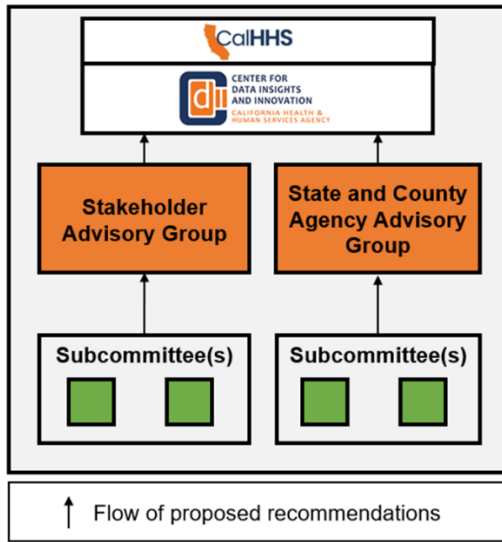
## V. Governance Model Structure and Implementation Approach

Data Exchange Framework Governance must balance the need to move quickly with the need for transparency, ongoing and robust stakeholder engagement, and oversight. It will establish a strong role for the state to lead the implementation, oversight, and ongoing refinement of the Data Exchange Framework with multi-stakeholder committees to provide input, transparency, and oversight.

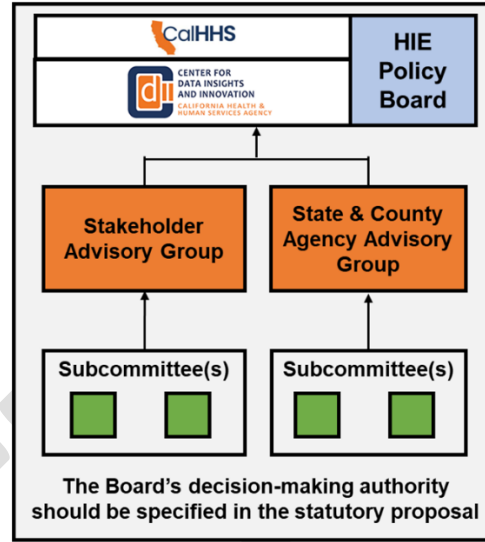
Taking these factors into account, Data Exchange Framework Governance will be implemented in two phases, as shown in the graphic below. On July 1, 2022, the Data Exchange Framework will be launched, with CalHHS and CDII managing and overseeing all aspects of governance. CalHHS will seek to develop a legislative proposal by January 2023 to establish an HIE Policy Board that year.



July 1, 2022: Launch the DxF with CDII managing & overseeing all aspects of Governance



2023: Establish HIE Policy Board to manage and oversee major DxF program and policy decisions



Depending on how the HIE Policy Board is established, the HIE Policy Board will have decision-making authority for a set of oversight activities. Decision-making authority would be specified in the statutory proposal. It should be chaired by the Secretary of CalHHS and be comprised of at least five and no more than seven other organizations, the majority of which should be appointed by the Governor and the remaining individuals should be appointed by the legislature. HIE Policy Board membership may include ex-officio members of the California Public Employee Retirement System (CalPERS) and Covered California. Consumer representation on the board will be critical given the focus of the Data Exchange Framework on improving the health and wellbeing of individual Californians. Board members will be subject to strict conflict-of-interest policies.

Once the HIE Policy Board is established, CDII will be responsible for supporting core day-to-day governance activities and functions.

Upon the launch of the Data Exchange Framework, two advisory groups will be established that provide mechanisms for stakeholders to advise the state on HIE policies and programs. CDII will convene these advisory groups and support other stakeholder engagement activities to advance policy and program recommendations, including those that may be elevated to the HIE Policy Board for consideration.

Advisory groups will be appointed by CalHHS and may reflect the composition of the Data Exchange Framework Stakeholder Advisory Group specified in AB133 [§130290(c)(2)]. One Stakeholder Advisory Group will be composed of representatives from public- and private-sector organizations, and a second State and County Agency Stakeholder Advisory Group will be composed of representatives from state and county agencies and departments.

Each advisory group may be supported by one or more subcommittees, which will be formed at the request of CalHHS/CDII and the applicable Advisory Group. Subcommittees will also operate under domain-specific charges prescribed by CalHHS/CDII, and members will be appointed by CalHHS/CDII.

Data Exchange Framework Governance provides a strong foundation from which the Data Exchange Framework can be successfully implemented, overseen, and refined. Establishing an HIE Policy Board will ensure that advancing the Data Exchange Framework will remain a priority for years to come. It also provides critical stakeholder input on major program and policy decisions. Day-to-day oversight and operational activities should remain with CalHHS/CDII, allowing the Board to focus on decisions it is legislatively charged with making. Advisory Groups and Subcommittees provide formal forums for a broader range of stakeholders to provide input on program and policy development. Additionally, deliberations of the HIE Policy Board, Advisory Groups, and Subcommittees will be held in open meetings, providing additional transparency and opportunities for public input as policy and program recommendations are formulated.

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