

Data Exchange Framework Development Process Overview

Section Draft
May 12, 2022

Overview

On July 27, 2021, Governor Newsom signed [AB133](#), enacting Health and Safety Code Section 130290 and putting California on the path to building a statewide Health and Human Services Data Exchange Framework (DxF): a single data sharing agreement and common set of policies and procedures that will govern the exchange of health information among health care entities and government agencies beginning in June 2024. AB133 also requires the California Health and Human Services Agency (CalHHS) to “develop in consultation with the stakeholder advisory group [...] a strategy for unique, secure digital identities capable of supporting master patient indices to be implemented by both private and public organizations in California” by July 31, 2022.

This document details the process by which CalHHS and the Center for Data Insights and Innovation (CDII) developed the DxF, its Data Sharing Agreement and Policies and Procedures, and the Strategy for Digital Identities. DxF development was guided by the requirements and deadlines set out by AB133 and was informed by extensive stakeholder engagement.¹

Data Exchange Framework

Per AB133, the DxF will, among other aims, “identify gaps, and propose solutions to gaps, in the life cycle of health information, including gaps in...

- Health information creation, including the use of national standards in clinical documentation, health plan records, and social services data.
- Translation, mapping, controlled vocabularies, coding, and data classification.
- Storage, maintenance, and management of health information.
- Linking, sharing, exchanging, and providing access to health information.”

AB133 required CalHHS to “convene a stakeholder advisory group... to advise on the development and implementation of the California Health and Human Services Data Exchange Framework.” The DxF Stakeholder Advisory Group, comprising a diverse set of representatives from 27 stakeholder organizations and 14 state departments, was convened in August 2021 and met approximately monthly thereafter until June 2022.^{2,3} The Stakeholder Advisory Group was regularly engaged to offer input on key CalHHS DxF development decisions.

¹ Stakeholder engagement for the DxF, its Data Sharing Agreement and Policies and Procedures, and the Strategy for Digital Identities was conducted in accordance with the requirements of the Bagley-Keene Open Meeting Act.

² A complete roster of Stakeholder Advisory Group members can be found on CalHHS' Data Exchange Framework [website](#).

³ Presentations, recordings, summaries, public comments, and other materials from all Stakeholder Advisory Group meetings can be found on CalHHS' Data Exchange Framework [website](#).

During its first meeting, the Stakeholder Advisory Group discussed CalHHS' proposed vision for data exchange in California, the Stakeholder Advisory Group's [charter](#), and the need for a Data Sharing Agreement (DSA) Subcommittee to support the development of the Data Sharing Agreement and Policies and Procedures.

CalHHS/CDII subsequently requested that the Stakeholder Advisory Group confirm its assessment of health and human service electronic information exchange gaps – as surfaced through the development and analysis of six data exchange “scenarios” – and provide feedback on the [Guiding Principles](#) that would be used to resolve those gaps.

The Stakeholder Advisory Group provided further counsel on gap resolution strategies (i.e., “opportunities”) and provided input on the development of the DxF's Data Sharing Agreement, Policies and Procedures, and Strategy for Digital Identities.

CalHHS/CDII incorporated input from the Stakeholder Advisory Group and members of the public before advancing materials and recommendations to the CalHHS Secretary for final consideration.

Data Sharing Agreement and Policies and Procedures

AB133 required CalHHS to consult with stakeholders and local partners to establish, on or before July 1, 2022, the California Health and Human Services Data Exchange Framework, which “includes a single data sharing agreement and common set of policies and procedures that will govern and require the exchange of health information among health care entities and government agencies in California.” While the DxF codifies a set of foundational Guiding Principles and a robust vision for data exchange, the Data Sharing Agreement is the legal agreement that defines the signatories' obligations and requirements for participation in data exchange. The Data Sharing Agreement is supported by a set of policies and procedures that contain detailed guidance, technical specifications, and processes to support implementation. The policies and procedures will evolve and be refined over time by processes determined by the DxF Governance process.

A Data Sharing Agreement Subcommittee consisting of 23 members was convened on November 8, 2021.⁴ As per the Data Sharing Agreement Subcommittee [charter](#), the subcommittee operated based on consensus and did not have decision-making authority. CalHHS/CDII convened the DSA Subcommittee approximately monthly between November 2021 and April 2022 to provide input on key development decision points; these decision points were then presented back to the broader Stakeholder Advisory Group.⁵

⁴ A complete roster of Data Sharing Agreement Subcommittee members can be found on CalHHS' Data Exchange Framework [website](#).

⁵ Presentations, recordings, summaries, public comments, and other materials from all Data Sharing Agreement Subcommittee meetings can be found on CalHHS' Data Exchange Framework [website](#).

At the January 18, 2022 meeting and for the next two meetings, on February 23 and March 22, the Data Sharing Agreement Subcommittee reviewed and provided feedback on initial drafts of topics for the Data Sharing Agreement and Policies and Procedures.

Based on input provided by the Stakeholder Advisory Group, the Data Sharing Agreement Subcommittee, and the public, CalHHS developed drafts of the Data Sharing Agreement and an initial set of Policies and Procedures for public comment. CalHHS discussed the drafts at the April 26, 2022 Data Sharing Agreement Subcommittee meeting.

At its May 18, 2022 meeting, the Stakeholder Advisory Group reviewed updated drafts of the Data Sharing Agreement and the initial set of Policies and Procedures. CalHHS subsequently posted drafts of the Data Sharing Agreement and the initial set of Policies and Procedures on the CalHHS website for continued public comment.

CalHHS revised the Data Sharing Agreement and the initial set of Policies and Procedures and posted final versions on the CalHHS website on [final date to be inserted].

Strategy for Digital Identities

AB133 required CalHHS to “develop in consultation with the stakeholder advisory group... a strategy for unique, secure digital identities capable of supporting master patient indices to be implemented by both private and public organizations in California.” The Strategy for Digital Identities comprises a component of the Data Exchange Framework by beginning to address a gap identified by the Stakeholder Advisory Group for coordinated person identity matching services needed to improve effective exchange of health and human service information.

Developing a robust and effective Strategy for Digital Identities required input from industry experts representing public and private stakeholders potentially implicated by the strategy’s design and implementation. In addition to consultation with the Stakeholder Advisory Group per AB133, CalHHS convened a series of focus groups to capture diverse stakeholder perspectives, ultimately engaging over 50 strategic, technical, and operational experts inside and outside of California representing:⁶

- Health information exchange organizations;
- Consumer privacy advocates;
- Health care providers;
- Health plans;
- Human service organizations; and
- California state agencies and departments.

⁶ Complete rosters for each focus group can be found on CalHHS’ Data Exchange Framework [website](#).

Each focus group met twice in public meetings from late January through March 2022. As CalHHS developed its Strategy for Digital Identities, it sought focus group and public feedback on:

- The purpose and use cases for digital identities within the Data Exchange Framework;
- Elements of a digital identity that would enable more effective data exchange;
- Standards for data attributes in a digital identity;
- Permitted use of digital identities and limitations on secondary use to protect privacy;
- The role of master person indices and a potential statewide index; and
- Barriers to adoption of a California strategy for digital identities.

High-level concepts used to develop the Strategy for Digital Identities and overarching questions were brought to the Stakeholder Advisory Group in its spring 2022 meetings for input before a draft strategy was presented and discussed at the Stakeholder Advisory Group meeting on April 7, 2022. Key concepts regarding technical standards, security, and permitted uses of digital identities were also discussed with the DSA Subcommittee for inclusion in the Data Sharing Agreement and Policies and Procedures. The Strategy for Digital Identities, while a separate legislatively required product, is also cross-referenced in the DxF and its Data Sharing Agreement and Policies and Procedures.