

California Health & Human Services Agency

Center for Data Insights and Innovation

Data Exchange Framework Roadmap 2025–2027

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Executive Summary

Established by AB133 in 2021, California’s [Data Exchange Framework](#) (DxF) is the first statewide Data Sharing Agreement (DSA) to securely exchange Health and Social Services Information (HSSI) among health and social service organizations and government agencies in California. The DxF requires hospitals, physician organizations and medical groups, health plans, other statutorily-mandated entities to sign the DSA to exchange HSSI in real time starting January 31, 2024, in accordance with the DSA and its Policies & Procedures (P&Ps). The California Health & Human Services Agency’s (CalHHS) Center for Data Insights and Innovation (CDII) oversees the DxF.

CDII developed this **DxF Roadmap** to identify and communicate a set of DxF implementation priorities; and proposed steps and milestones to implement them through 2027.

This Roadmap is to serve as a guide for the whole state. It describes how we can work together and collectively invest in data exchange efforts to advance whole person care initiatives. It is intended to reflect the desires and needs of communities, agencies and stakeholders who are advancing health and social service initiatives. The Roadmap contemplates leveraging efforts across the health and human service ecosystems, including those both inside and outside of government. And it is intended to reflect the spirit and intent of AB 133 that put the Data Exchange Framework into law.

The DxF Roadmap describes issues, goals, opportunities, and recommendations across six priority areas (or “Pillars”) as shown in the table below. Priority areas were identified in partnership with stakeholders and to align with other CalHHS priorities, including California Advancing and Innovating Medi-Cal (CalAIM).

Priority Area/Pillar	Goal Statement
Event Notification	Establish a common, statewide structure to communicate significant events that impact an individual’s health to all authorized DxF Participants that request them to improve whole person care.
Social Service Data Strategy	Establish scalable social service and health data exchange to connect individuals to the programs and services they need and enable care coordination.
Consent and Identity Management	Develop a statewide consent and digital identity management framework that allows individuals to provide, update, and revoke their consent to share protected Health and Social Service Information between their care and social service partners.
Public Health	Accelerate the adoption and use of interoperable data systems for public health activities.
Impact Measurement	Measure the DxF’s impact on data exchange, health and social services delivery, and health outcomes, and leverage these measures to inform future DxF design considerations.
Participant Engagement	Strengthen pathways and processes to engage with mandatory and voluntary DSA signatories to increase participation in and compliance with the DxF and enhance DxF Participant monitoring.

The recommendations and actionable steps described for each of these priority areas will serve as a workplan to guide CDII and partner activities over the next three years. The Roadmap recommendations address issues and propose solutions across three categories:

- Regulations, Policies, and Guidance
- Technical Infrastructure, Architecture, and Standards; and
- Financing, Contracting, and Operations

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Introduction

Purpose of the Data Exchange Framework Roadmap

The purpose of the **Data Exchange Framework (DxF) Roadmap** is to:

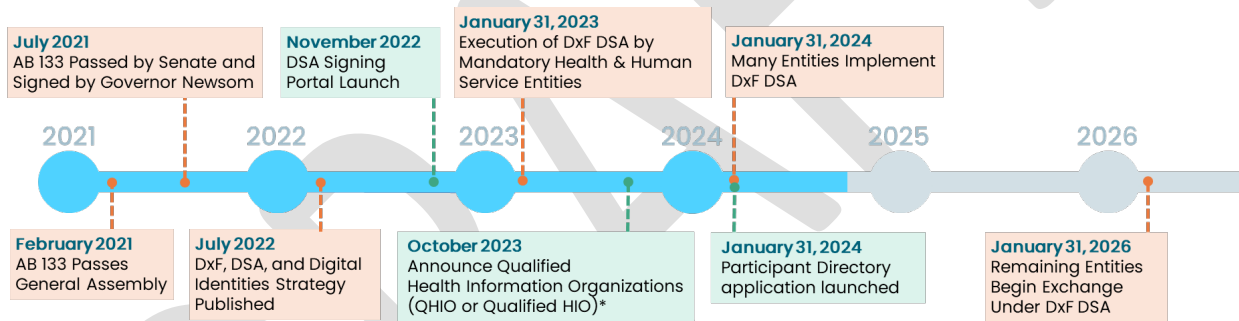
- Identify and communicate a set of DxF implementation priorities; and
- Propose actionable steps and milestones to be pursued by the state and relevant stakeholders over the course of 2025–2027.

The Center for Data Insights and Innovation (CDII) collaborated with a broad range of stakeholders to develop the Roadmap, including the DxF Implementation Advisory Committee (IAC), CalHHS state departments, and other subject matter experts. Feedback received during a period of public comment in Fall 2024 also informed the Roadmap’s final recommendations.

The recommendations described in this Roadmap will serve as an actionable plan for CDII and relevant stakeholders to advance critical data exchange priorities in 2025-2027.

DxF Background

Figure 1. DxF Implementation Timeline



What is the DxF? Established by AB133 in 2021, the DxF is California’s first statewide data sharing agreement to securely exchange HSSI among health and social service organizations and government agencies in California. The DxF requires hospitals, including psychiatric hospitals, physician organizations and medical groups, skilled nursing facilities, health plans, clinical labs, and others who may voluntarily choose to sign the DSA to exchange HSSI in real time starting January 31, 2024, in accordance with the DSA and its Policies & Procedures (P&Ps). The DSA and its P&Ps require signatories to share information in alignment with all federal and state law.

In addition to developing the DSA and its P&Ps, CDII has established additional program elements to support DxF signatories in exchanging data. These elements include:

- **DxF Grants Program:** The DxF Grants Program is comprised of (1) DxF Educational Initiative Grants; and (2) DSA Signatory Grants. The DxF Educational Initiative Grants provided \$2.8 million in funding to eight non-profit associations to deliver DxF-related education and training in calendar year 2023. Through its Signatory Grant program, CDII awarded close to \$47 million across 745 DxF signatories to supporting establishment of systems and processes to facilitate exchange and compliance with DxF requirements.

- **Qualified Health Information Organization (QHIO) Program:** QHIOs are data exchange intermediaries that have been designated by CDII to facilitate the exchange of HSSI between DxF signatories. The Program helps ensure that a broad range of signatories – including those with limited resources or technological capacity – have options to support them in securely sharing information under the DxF.
- **DxF Participant Directory (PD):** The DxF Participant Directory provides DxF Participants with access to information about the exchange choices of other Participants. Participants are required to complete the PD after signing the DSA as a means of communicating to other Participants their preferred means of sending and receiving data.

The DxF was established in partnership with public stakeholder advisory committees with representatives from health and social service organizations, government agencies, consumers, and privacy advocates, among others. These advisory committees continue to meet regularly to provide counsel to CalHHS and CDII in the development and implementation of the DxF and its related programs.

Overview of Roadmap Structure

CDII developed the DxF Roadmap to define priorities for the next phase of DxF implementation.

The Roadmap includes a chapter for each of six identified DxF priority areas (or “Pillars”). The six priority areas are:

1. **Event Notification**
2. **Social Service Data Strategy**
3. **Consent and Identity Management**
4. **Public Health**
5. **Impact Measurement**
6. **Participant Engagement**

Each chapter includes a description of the goals, issues, and recommendations for the priority area. Specifically, each chapter will include a description of:

- **Background, issues, goals, and tenets**
- **Current state, problem definition, and opportunities for resolution**
- **Recommendations**
- **Actionable steps**

Each priority area is in a different stage of planning and implementation. As a result, some recommendations differ in specificity and granularity. It is also important to note that the Roadmap describes an action plan for advancing CDII’s data exchange priorities at a point in time. As the plan is implemented, it will therefore need to be updated to reflect implementation progress and to respond to an evolving data exchange landscape.

Together, the recommendations described in this Roadmap will provide a comprehensive view of DxF priorities in 2025–2027 and serve as an actionable plan to improve data exchange and the health and wellbeing of all Californians.

Pillar #1: Event Notification

Introduction

Background of Issues

Knowledge of admissions and discharges from acute care settings is necessary to improve care coordination, care transitions and whole person care while reducing total cost of care. However, there are currently no coordinated nationwide networks or California statewide initiatives for providing notifications of admissions and discharges.

The Centers for Medicare & Medicaid Services (CMS) established certain requirements in its 2020 Interoperability and Patient Access Final Rule for hospitals to send notifications of admissions and discharges to a patient's primary care provider (PCP) and other providers identified by the patient as part of Conditions of Participation in Medicare and Medicaid programs. The Final Rule, however, does not establish clear technical standards or an architecture for reporting admissions and discharges. It also places the burden of identifying providers that should receive notifications on the patient, which often results in the exclusion of key members of the care continuum.

The DxF established the notification of admissions and discharges as a required exchange type for hospitals and emergency departments (EDs) that are DxF Participants. However, the DxF does not establish a common statewide structure or technical specifications for notifications. Additionally, admissions to and discharges from acute care settings remain the focus of nearly all notification initiatives, including the initial DxF requirements, ignoring other events that may likewise impact whole person care.

Goal

The goal of the DxF Roadmap Event Notification Pillar is to establish a common, statewide structure to communicate significant events that impact an individual's health to all authorized DxF Participants that request them to improve whole person care.

Central Tenets

The following tenets will guide the development of this Pillar's recommendations:

1. Only send DxF Participants the HSSI they request. Assume DxF Participants can and likely will request more information they need if made aware of an event significant to them or the individual.
2. Do not stifle innovation.
3. Design for large-scale implementation.
4. Minimize barriers to participation, prioritizing minimizing barriers for those that request notifications over those that must provide notifications when necessary.
5. Build on what already exists whenever possible.

Landscape

Summary of Current State

The DxF Builds upon Federal Event Notification Requirements.

In 2020, the CMS Interoperability and Patient Access Final Rule established a requirement for hospitals to provide admission and discharge notifications to a patient’s PCP and other providers identified by the patient.¹

The DxF instead required hospitals and EDs, and encouraged skilled nursing facilities (SNFs), to send notifications of admissions and discharges to any authorized DxF Participant that requests them.² DxF also established a mechanism for identifying recipients of notifications that differs from the CMS Final Rule by requiring DxF Participants to request notifications by submitting a roster containing the identities of individuals for which notifications were requested.

In the absence of a nationwide network or framework for communicating notifications, DxF P&Ps opted for flexibility in how event notifications are requested and delivered. DxF Participants that are hospitals, EDs, and SNFs are individually allowed to determine the method and format for submitting rosters, requiring only that rosters conform to DxF person-matching requirements.² DxF Participants that are hospitals, EDs, and SNFs are also individually allowed to determine the content and format of notifications they transmit, and the method for sending notifications. The lack of specific technical standards for event notification has led to confusion and administrative burden among DxF Participants.

California’s QHIOs Establish Some Event Notification Standardization.

The DxF QHIO Program requires QHIOs to exchange rosters, receive admission and discharge event messages from DxF Participant hospitals, EDs, and SNFs who are their customers, and send admission and discharge notifications to other QHIOs based on the rosters they exchange. Many QHIOs had an existing event notification service in place prior to becoming a QHIO. All the QHIOs that described their existing notification service to the state support rosters as the mechanism to request notifications, with many using that method exclusively. Most QHIOs support several methods for “sending” notifications, including:

- Transmitting alerts into an electronic health record (EHR);
- Sending notifications via secure messaging or secure email;
- Listing notifications on a portal to which providers log in; or
- Sending lists of notifications on a regular basis via a fax gateway.

¹ [“Medicare and Medicaid Programs; Patient Protection and Affordable Care Act; Interoperability and Patient Access for Medicare Advantage Organization and Medicaid Managed Care Plans, State Medicaid Agencies, CHIP Agencies and CHIP Managed Care Entities, Issuers of Qualified Health Plans on the Federally-Facilitated Exchanges, and Health Care Providers”](#), Fed. Reg. 85, Reg. 85, 1-131 (May 1, 2020).

² Technical Requirements for Exchange Policy and Procedure v1.0.1

QHIOs are collaborating to develop a standard format and mechanism for exchanging rosters with other QHIOs. They agreed on a preference for exchanging events with other QHIOs via HL7 ADT messages.

Event Notification Interest Extends to Public Health.

In 2024, the California legislature passed SB159³ which provides the California Department of Public Health (CDPH) with new legal authority to collect and require syndromic data submissions from hospitals with EDs. This legislation requires use of messaging standards published by the U.S. Centers for Disease Control and Prevention (CDC).⁴ Hospitals with EDs are required to deidentify and report specific event types for all patients, not just for those found on a roster. This new requirement illustrates the growing interest in event notification for use cases beyond care coordination.

Other National and State Models Offer Perspective on Potential Pathways Forward.

The Massachusetts Health Information Highway (Mass HIway) established a statewide Event Notification Service⁵ (ENS) to alert providers about their patients' admissions to and discharges from hospitals, EDs, and post-acute care facilities. Like California's DxF, providers on Mass HIway may subscribe to notifications of admissions and discharges based on a roster of patients. Unlike DxF, however, Mass HIway's ENS establishes a coordinated architecture wherein hospitals, EDs, and post-acute care facilities must send event messages to one of a small number (currently two) state-selected ENS vendors. Mass HIway's ENS vendors share messages with each other, process patient rosters, forward notifications to providers when matched to a roster, and discard the event if no match is found.

Patient Centered Data Home™⁶ (PCDH) offers a different model for event notifications dependent upon a network of cooperating health information exchanges (HIEs), each serving a defined geography (i.e., a "patient's data home"). Within PCDH, a participating HIE checks the home ZIP code of the patient for which it receives an admission or discharge message. If that ZIP code is not served by that HIE, the HIE seeks to identify the HIE(s) that serve that ZIP code (if any) using PCDH's centralized directory and forwards the message to the so-identified HIE(s). If the recipient HIE recognizes the patient, it may act upon the message in several ways depending upon how it serves its clients:

- Saving the event as part of the longitudinal community record for the patient;
- Sending a notification of the admission or discharge to members of the patient's care team;
- Sending a return message to the sending HIE notifying it that health information on the patient may be available for exchange using other methods, such as a nationwide network; and/or

³ California State Legislature. [Senate Bill No. 159](#) (2023-2024).

⁴ Centers for Disease Control and Prevention. "PHIN Messaging Guide for Syndromic Surveillance: Emergency Department, Urgent Care, Inpatient and Ambulatory Care Settings." Accessed October 23, 2024. https://www.cdc.gov/nssp/documents/guides/syndrsurvmessagguide2_messagingguide_phn.pdf

⁵ The Massachusetts Health Information Highway. "Statewide ENS Framework." Accessed October 23, 2024. https://www.masshiway.net/Services/Statewide_ENS_Framework

⁶ Civitas Networks for Health: "Patient Centered Data Home." Accessed October 23, 2024. <https://www.civitasforhealth.org/wp-content/uploads/2022/08/Civitas-PCDH-Datasheet-2022-08-21.pdf>

- Requesting additional information on the subject patient and event such as admission notes or a discharge summary, again using other methods such as a nationwide network.

PCDH does not depend upon rosters for sharing event notifications, but instead sends notifications to HIEs based on an assumption that an appropriate recipient can be identified based on service geography, and that the recipient may be authorized to receive and use the notification and will act upon it appropriately.

Some QHIOs intend to participate in PCDH. Some California stakeholders have expressed concern that sending notifications based solely on geographic service area may not properly respect patient privacy. Further, the PCDH approach violates the first tenet of this Pillar by sending notifications to organizations that have not requested them.

Outside of PCDH, no nationwide network or framework—including eHealth Exchange, Carequality, CommonWell Health Alliance, or the Trusted Exchange Framework and Common Agreement (TEFCA)—provides a framework, an architecture, or technical standards for event notifications that DxF can leverage. Notifications of admissions and discharges is not yet being discussed as a capability of Qualified Health Information Networks (QHINs) or TEFCA, nor does it currently appear on any TEFCA roadmap.

[Problem Definition, Issue Identification and Critical Challenges](#)

Issue Statement

There is no coordinated, statewide method in California for those providing health and social services to remain informed of significant events impacting the health of those they serve, creating gaps in care coordination among health care providers, health plans, social services providers, and government agencies and missing opportunities to improve whole person health.

Three critical barriers to exchanging event notifications in California include the lack of common architecture, technical standards, and method for identity matching.

Issue #1: Lack of Common Architecture

There is no overarching, common, statewide architecture for sending and receiving event notifications in California. DxF Participants and advisory group members have expressed a desire to use rosters to request notifications, consistent with the first tenet of this Pillar. However, there is likewise no overarching, common, statewide architecture for collecting and processing rosters. The lack of a common architecture results in significant barriers and burdens for both those receiving and those sending notifications:

- Those wishing to receive notifications must submit rosters to hundreds of organizations;
- Those required to send notifications must receive and manage rosters from hundreds of organizations, with some rosters likely identifying millions of patients;
- Those required to send notifications must send them to many organizations; and
- Those receiving notifications will receive them from many organizations, in different formats, with different content, and using different exchange methods, including some methods that are inconvenient to integrate into their workflows.

Based on the current sample of DxF Participants entering their choices in the DxF Participant Directory, approximately half of hospitals have chosen not to use a QHIO to manage rosters or send notifications and approximately one in five ambulatory providers have not onboarded to a QHIO.⁷ These statistics suggest that:

- All QHIOs and at least 20% of ambulatory providers would be required to submit rosters to hundreds of hospitals, EDs, and SNFs in order to receive all potential notifications of admissions and discharges; and
- Half of hospitals would have to process rosters from hundreds of DxF Participants, setting up unique point-to-point connections to each one in order to communicate notifications.

The lack of a common, statewide architecture creates fragmentation and presents potentially untenable burden on DxF Participants required to send and desiring to receive event notifications across California.

Issue #2: Lack of Common Technical Standards

The DxF has leveraged the technical standards in use by nationwide networks and frameworks, notably including TEFCAs, when establishing technical requirements for many exchange types. However, the DxF did not establish technical standards for communicating events or notifications due to a lack of national initiatives to leverage. The lack of specific technical standards in the DxF's event notification requirements increases the complexity and burden:

- For those submitting rosters to many organizations using different formats and methods;
- For those receiving notifications from many organizations using different formats and methods; and
- For intermediaries that must support many technical standards and translate among them to meet their customers' capabilities to receive notifications.

For many providers without strong information technology support or sufficient administrative staff, the complexity and fragmentation created by the lack of standards puts submitting rosters and processing notifications out of reach.

Issue #3: Lack of a Common Individual/Patient Identity

Organizations required to receive rosters and send notifications need to match the identities of individuals on a roster to the identities of individuals that are the subject of an event. The DxF Strategy for Digital Identities⁸ established a common set of attributes to be used by DxF Participants to match identities of individuals within different systems and care settings. DxF Policies and Procedures established requirements to use these attributes, including for identities in rosters and transmitted events and notifications.

⁷ Statements are based on choices entered by one third of DxF Participants in the DxF Participant Directory for how they exchange Health and Social Services Information.

⁸ Center for Data Insights and Innovation, California Health and Human Services Agency. "[Strategy for Digital Identities](#)." July 1, 2022.

However, most DxF Participants have minimal access to sophisticated technologies capable of effective person matching. Estimates suggest that typical matching methods implemented in EHRs may identify as few as 30% of records belonging to an individual.⁹ QHIOs utilize much more sophisticated matching technologies. However, QHIOs have expressed that the cost of person matching using these technologies may be prohibitive on a statewide scale that includes very large rosters.

Opportunities for Resolution

California could pursue several opportunities, as listed in the table below, to resolve the barriers to effective statewide event notification.

Table 1. Summary of issues and opportunities to resolve them

Issue	Opportunities
Lack of Common Architecture	<ul style="list-style-type: none">• Establish a structure for submitting, managing, and accessing rosters• Establish a structure for submitting events, matching them to rosters, and communicating notifications
Lack of Common Technical Standards	<ul style="list-style-type: none">• Establish minimum required method for submitting rosters• Establish minimum technical standards for content and method of exchange by which DxF Participants communicate events to intermediaries• Establish minimum technical standards for content and method of exchange of notifications to DxF Participants that request them• Preserve technical options to avoid stifling innovation
Lack of Common Individual Identity	<ul style="list-style-type: none">• Establish minimum technical standards for content and format for rosters• Collaborate with other Pillars to establish a common method of establishing individual identity on DxF

Cross-enterprise information sharing in health care is dominated by query-based exchange—that is, an organization requests information from another organization in advance of, during, or following an encounter. Query-based exchange is supported on all nationwide networks and frameworks, including TEFCA, is the focus of most emerging technical standards such as Fast Healthcare Interoperability Resource (FHIR), and is required of all DxF Participants.

DxF stakeholders have called for an increase in so-called push-based exchange, i.e., sending information to an organization rather than waiting for the organization to request it. This approach is thought to provide more timely and complete awareness of an individual’s health status. Push-based exchange is

⁹ Eric Heflin, Shan He, Kevin Isbell, et al, [A Framework for Cross-Organizational Patient Identity Management](#) (The Sequoia Project, 2018).

supported on nationwide networks and frameworks (although TEFCA has delayed implementation) but is seldom implemented or used by network/framework participants. Receipt of Health and Social Services Information by push-based exchange is optional for DxF Participants. Push-based exchange may lead to information overload, a common complaint of health care providers receiving unsolicited discharge summaries from hospitals implementing Direct secure messaging as part of their compliance with Meaningful Use requirements. Push-based exchange also violates the first tenet of this Pillar to only send DxF Participants the Health and Social Services Information they request unless the exchange is in response to an order or referral that has been requested.

This Pillar recommends a new exchange type for standardized event notification to be known as “Event-Based Exchange.” Event-Based Exchange would support the notification of significant events that impact the health of an individual among health care and social service organizations as requested by a DxF Participant. In response to notification of an event, a DxF Participant may then choose whether to retrieve more information about the event through query-based exchange.

Recommendations

The following are recommended activities for the state to establish and promote Event-Based Exchange on the DxF, to be led by the Center for Data Insights and Innovation in collaboration with DxF Participants and other stakeholders.

Technical Infrastructure, Architecture, and Standards

1. **Establish a logical architecture** for Event-Based Exchange that supports:

- Submitting, managing, and accessing rosters;
- Communicating events;
- Matching roster identities to individuals that are the subjects of events; and
- Routing notifications to those requesting them.

In addition to DxF Participants that communicate events and receive notifications, actors in the architecture might include QHIOs, other intermediaries, and/or centralized services.

2. **Explore establishing centralized or coordinated federated services** to support Event-Based Exchange, including:

- Person matching to increase consistency and reduce burden of linking individuals on a roster to the subjects of events and notifications;
- Submitting, managing, and accessing rosters; and/or
- Submitting and routing events, and delivery of notifications.

Since Health and Safety Code (HSC) § 130290 requires that DxF Participants be allowed to use “any health information exchange network, health information organization, or technology that adheres

to [DxF] standards and policies”,¹⁰ adoption of any single centralized or coordinated services would likely need to be voluntary.

Some stakeholders, notably QHIOs, may not be in full support of centralized statewide services, especially if duplicative of their own capabilities or disruptive of their business models. While establishing a logical architecture may be critical to the success of statewide Event-Based Exchange, establishing centralized services is less critical.

3. Establish minimum technical standards for:

- Content and format of a roster;
- Information communicated in an event or notification; and
- Method(s) for exchanging an event or notification.

While the initial DxF use case is for admissions to and discharges from acute and subacute care facilities, technical standards should support the expansion to other types of events. Content standards for events and notifications should be minimal to align with the first tenet of this Pillar and to reduce burden on senders and receivers, but be sufficient to be actionable by recipients, allowing them to make decisions on whether to request additional information. Requirements should focus on minimum standards, allowing for DxF Participants to explore alternatives and innovate.

An important part of this effort is to clarify the requirements for attributes used to identify individuals in rosters, events, and notifications as necessary.

Regulations, Policies, and Guidance

1. **Promote the concept of Event-Based Notification** and its architecture by naming it in DxF Policies and Procedures and generalizing the current requirement for Notifications of ADT Events as the initial use case for Event-Based Exchange. Leverage the QHIO Program where possible to realize the architecture, potentially requiring QHIOs to participate in specific role(s) within the architecture. Leverage TEFCA in the architecture whenever possible, such as promoting its use to request additional information on an event after receiving a notification.
2. **Require the use of minimum technical standards** by applicable DxF Participants, including QHIOs, through amendments to applicable DxF Policies and Procedures. Allow the use of alternative technical standards if both parties agree to their use in order to promote innovation. Development and use of FHIR standards might be especially encouraged. Continue to monitor the development of TEFCA for signs that event notifications may become a supported exchange type and ensure the DxF standards for Event-Based Notification are compatible.
3. **Advance use cases beyond Notification of ADT Events** through discussions with CalHHS Departments and DxF stakeholders. Work with stakeholders to define use cases that leverage Event-Based Exchange. Promote exploration of how to implement use cases within the DxF Sandbox. Encourage the DxF Sandbox to publish industry guidance on how Event-Based Exchange can be used beyond admissions to and discharges from acute and subacute care facilities.

¹⁰ [California Health and Safety Code, Div. 109.7, California Health and Human Services Data Exchange Framework § 130290 \(a\)\(2\).](#)

Financing, Contracting, and Operations

1. **Promote the use of centralized services** by using CalHHS Department contractual levers and by reducing barriers to their use (e.g., cost reduction and simplified technical methods). Ensure that centralized services provide value to QHIOs, and leverage the QHIO Program, Department contractual levers to use QHIOs, and significant voluntary use of QHIOs by DxF Participants to create critical mass use of centralized services.
2. **Secure funding for initial development of centralized services** either as capabilities created by CalHHS or a state Department, or through grants to other entities to develop, govern, and operate the services. Explore sustainability models in discussions with industry, through requests for information (RFIs), and other means. Explore Federal Financial Participation (FFP) as a source of funding in collaboration with the Department of Health Care Services (DHCS). Ensure that early use cases support Medicaid members to maximize applicability of FFP to create and sustain the centralized services. Fund adoption of and connections to centralized services through grants and contracts if possible.
3. **Explore models for operating centralized services** by CalHHS, by a state Department, by a trusted non-profit, or by for-profit vendors. Explore governance models and identify sustainability models to reduce dependence upon the general fund and FFP.

Dependencies on Other Pillars

1. **Exchanging Health and Social Services Information** among organizations is dependent upon common, shared identities or robust person matching for the individuals that are the subject of exchange. This is especially true when attempting to match significant health events generated at one organization to the identity of an individual listed on a roster from another, including across health and social services domains. The DxF Roadmap Consent and Identity Management Pillar aims, among other things, to establish a “statewide consent and digital identity management framework.” The pursuit of this goal would significantly benefit this Pillar through developing a common statewide person matching service or statewide master person index accessible by all DxF Participants and establishing important guardrails in support of Event-Based Exchange.
2. **DxF Policies and Procedures require that a DxF Participant** only list on a roster those individuals for which the DxF Participant is authorized to receive notifications consistent with Applicable Law and any valid Authorizations, noting that notifications may include personally identifiable information, protected health information (PHI), and other Health and Social Services Information. In some cases, individual consent for the exchange of Health and Social Services Information may be required for a DxF Participant to request and receive event notifications, including for some sensitive data. For example:
 - In some instances, a covered entity may require consent to share notifications containing PHI with a non-covered entity.
 - A behavioral health, mental health, or substance use disorder (SUD) treatment provider may require consent to share notifications containing sensitive information with a health or social services provider or their intermediaries.
 - A social services organization may require consent (by its own policy) to share notifications containing information on service needs sensitive to the client to maintain client trust.

Scenarios/Use-Cases

DxF identified an initial use case in Notifications of ADT Events:

1. Communicating admissions to and discharges from acute and subacute care facilities to PCPs, other providers, and health plans.

This use case is already embodied in DxF Policies and Procedures as a required exchange type for some DxF Participants.

While the initial use case was limited to using rosters to notify recipients of specific types of events for identifiable individuals, event notification and Event-Based Exchange might have other permutations, including but not limited to:

- Using a roster to subscribe to notifications of many or all events impacting an individual (for example, to receive notification of hospital or ED admissions for high-risk individuals);
- Subscribing to notification of events of a specific type for all individuals without the use of rosters, which might include:
 - Notifications in which individuals are identified (for example, to receive notifications on all births), or
 - Notifications that are deidentified (for example, to receive deidentified notifications of all ED admissions for syndromic surveillance); and
- All DxF Participants receiving notification of a specific type of event without a specific request (for example, to ensure a change in an individual's consent status is communicated to all QHIOs, intermediaries, or DxF Participants serving that individual).

These permutations should be considered when developing new use cases. Some permutations, such as subscribing to all events without the use of rosters, may have privacy implications and may be limited by Applicable Law. Some permutations, such as receiving notifications for an event without a specific request, may violate the first tenet of this Pillar to only send information requested by a DxF Participant and might therefore be discouraged.

Other use cases identified in discussions with DxF Participants and in collaboration with state Departments include:

2. Communicating encounters with specialists providing care for a chronic condition (e.g., cardiologist, pulmonologist) to PCPs or health plans;
3. Communicating transfer events and other intra-facility events to health plans, including Med-Cal plans, to aid with utilization determination;
4. Communicating (de-identified) ED admissions and chief complaints to CDPH and/or local health jurisdictions (LHJs) to support syndromic surveillance;
5. Communicating life events (e.g., births, deaths, loss of employment, changes in housing status, and release from incarceration) that change eligibility for benefits to agencies that provide those benefits; and
6. Communicating any event to a case worker or care coordinator as part of CalAIM that impacts health and health needs, such as admissions, discharges, encounters with providers, changes in incarceration status, changes in employment, changes in housing, etc.

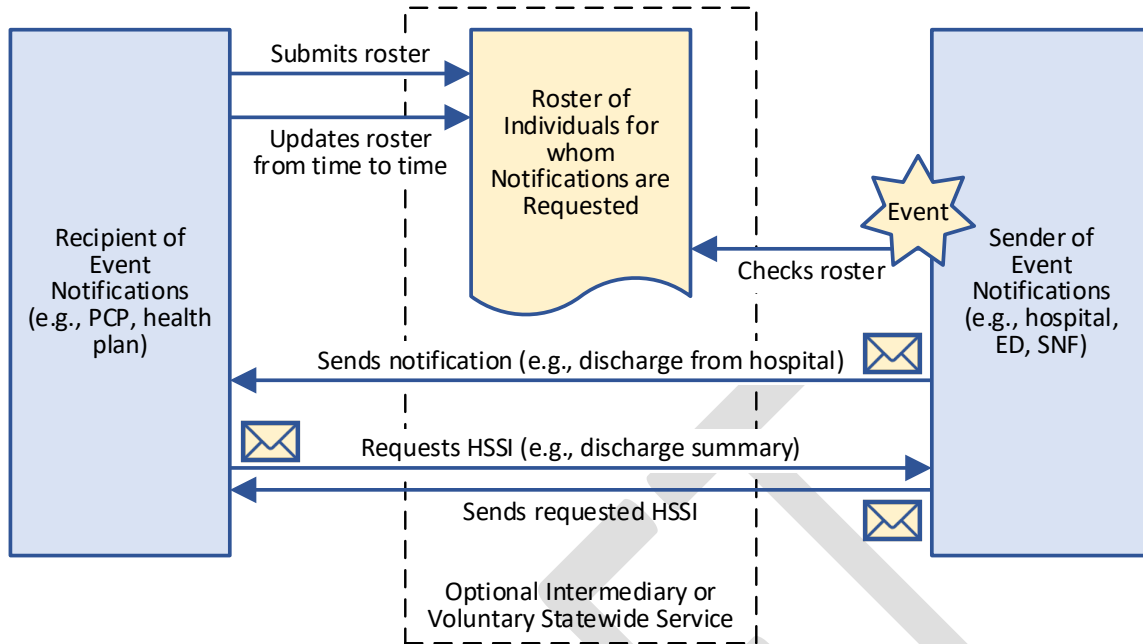


Figure 2. The process envisioned for Event-Based Exchange using the first use case for DxF as an example: submission of a roster, receipt of notification, and follow-up request for HSSI. Event-Based Exchange may take place between two DxF Participants, may use one or more intermediaries (such as a QHIO), or utilize voluntary statewide shared services.

Stakeholders have identified that event notification is not simply a technical issue to be addressed by a technical solution but must consider the workflows of those that receive notifications. Therefore, during use case development, it will be important to ensure that use cases:

- Allow organizations that receive a notification to properly delegate follow-up to an individual or organization responsible for the individual’s care; and
- Enable organizations to integrate the notification into the workflow of the recipient to reduce the barrier to taking advantage of additional situational awareness the notification affords.

Actionable Steps

<i>Regulations, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
Promote the concept of Event-Based Notification	Adjust Technical Requirements for Exchange P&P to name Event-Based Exchange and generalize Notifications for ADT Events	<ul style="list-style-type: none"> • Discuss how best to integrate Event-Based Exchange into clinical and social services workflows • Communicate advances in Event-Based Exchange in state and national forums 	<ul style="list-style-type: none"> • Discuss how best to integrate Event-Based Exchange into clinical and social services workflows • Communicate advances in Event-Based Exchange in state and national forums
Require the use of minimum technical standards	<ul style="list-style-type: none"> • Amend P&Ps to include new event notification standards • Amend P&Ps as necessary to clarify attributes of digital identity for person matching 	<ul style="list-style-type: none"> • New event and notification standards become effective • Expand P&Ps to include new use cases 	Expand P&Ps to include new use cases
Advance use cases beyond Notification of ADT Events	Work with Departments, QHIOS, DxF Participants, and other stakeholders to define, describe, and communicate new use cases and data requirements for Event-Based Exchange	Work with Departments, QHIOS, DxF Participants, and other stakeholders to define, describe, and communicate new use cases and data requirements for Event-Based Exchange	Work with Departments, QHIOS, DxF Participants, and other stakeholders to define, describe, and communicate new use cases and data requirements for Event-Based Exchange

<p><i>Technical Infrastructure, Architecture, and Standards</i></p>	<p>CY 2025</p>	<p>CY 2026</p>	<p>CY 2027</p>
<p>Establish a logical architecture for Event-Based Exchange</p>	<p>Develop initial logical architecture for Event-Based Exchange in collaboration with QHIOs, Departments, DxP Participants, and other stakeholders</p>	<ul style="list-style-type: none"> • Revise logical architecture to reflect learnings and shared service development details • Ensure architecture enables delegation to those responsible for follow-up activities and enables individual workflows 	<ul style="list-style-type: none"> • Revise logical architecture to reflect learnings and shared service development details • Ensure architecture enables delegation to those responsible for follow-up activities and enables individual workflows
<p>Explore centralized or coordinated federated services</p> <p><i>Procurement and implementation actions may be cancelled if appropriate solutions are not forthcoming or DxP Participants do not support their use.</i></p>	<ul style="list-style-type: none"> • Complete and evaluate RFI for shared roster service • Procure vendor or award grant for roster service and begin implementation • Establish linkage to statewide digital identity framework to support statewide person matching for rosters, events, and notifications 	<ul style="list-style-type: none"> • Shared roster service begins operation • Shared roster service utilizes statewide identity framework for person matching • Complete RFI for shared event routing and notification service • Procure vendor or award grant for event notification service and begin implementation 	<ul style="list-style-type: none"> • Shared event notification service begins operation • Leverage Impact Measurement to evaluate the impact of centralized services
<p>Establish minimum technical standards</p>	<p>Gather stakeholder input on event notification standards</p>	<ul style="list-style-type: none"> • Establish standards and format for rosters based on shared roster service • Evaluate need for standards adjustment based on new use cases 	<p>Evaluate need for standards adjustment based on new use cases</p>

<i>Financing, Contracting, and Operations</i>	CY 2025	CY 2026	CY 2027
Promote the use of centralized services		<ul style="list-style-type: none"> • Require that QHIOs use shared roster service • Explore and establish incentives for other DxF Participants to use shared services 	<ul style="list-style-type: none"> • Require that QHIOs use shared event routing and notification service • Explore and establish incentives for other DxF Participants to use shared services
Secure funding for initial development of centralized services	<ul style="list-style-type: none"> • Secure funding to develop shared roster service • Establish sustainability plan for shared roster service 	<ul style="list-style-type: none"> • Secure funding to develop shared event routing and notification service • Establish sustainability plan for shared event routing and notification service • Secure operational funding for Department shares of service use 	Maintain operational funding for Department share of service use
Explore models for operating centralized services	Establish governance and operational model for shared roster service	Establish governance and operational model for shared event routing and notification service	

Pillar #2: Social Service Data Strategy

Introduction

Background of Issues

Social determinants of health (SDOH) are “the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”¹¹ Addressing SDOH is crucial to advancing health equity, improving quality of care, and achieving better health outcomes. However, comprehensively identifying an individual’s SDOH needs and connecting them to the services they need is challenging due to the complex, multi-sector system in which these benefits and programs are delivered.

The DxF defines social services as “items, resources, and/or services to address social determinants of health and social drivers of health, including but not limited to housing, foster care, nutrition, access to food, transportation, employment, and other social needs.”¹² The robust exchange of social services data between clinical care providers and community-based organizations is a critical component to further understand and address whole person care. However, a lack of comprehensive technical standards for social service data, varying technological capabilities across service providers, and data privacy hurdles have created barriers to the exchange of this information at both the state and national level. Recent efforts by the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) and the HL7 Gravity Project have begun to outline guidance and standards for the exchange of SDOH information but this is still a nascent domain with limited examples at scale.¹³

Unlike other states that have a centrally organized health information exchange system, California’s landscape is a mosaic of local health information organizations (HIOs) that do not universally blanket health care providers. In addition, models of social service data infrastructures range from simple to sophisticated, from 211 service lookups to client-level multi-program information, and driven by local counties, payers, and private philanthropies. The availability of social services, whether publicly or privately funded, also varies significantly with differential rates of direct local county government versus private non-profit organization service provision. In sum, the variety of models of existing social and health care services adds to the challenge that cannot be solved by data sharing alone.

¹¹ U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. “Social Determinants of Health.” Accessed October 23, 2024. <https://health.gov/healthypeople/priority-areas/social-determinants-health>.

¹² Center for Data Insights and Innovation, California Health and Human Services Agency. “Data Exchange Framework (DxF) Glossary of Defined Terms.” Accessed October 23, 2024. [CalHHS-DxF-Glossary_v1.0.2_1.30.24_FINAL.pdf](#).

¹³ U.S. Department of Health and Human Services. “Social Determinants of Health Information Exchange Toolkit.” February 2023. https://www.healthit.gov/sites/default/files/2023-02/Social%20Determinants%20of%20Health%20Information%20Exchange%20Toolkit%202023_508.pdf

Goal

The goal of the DxF Roadmap Social Services Data Strategy Pillar is to establish scalable social service and health data exchange to connect individuals to the programs and services they need and enable care coordination.

Central Tenets

The following tenets will guide the development of this Pillar’s recommendations.

1. Build on existing health and social data exchange capabilities without interrupting existing/successful community data exchange activities and local trusted relationships with social service providers. The point here is that social/health data exchange is locally driven.
2. DxF/CDII is not responsible for creating new data sharing infrastructure and will leverage existing systems and emerging interoperability standards and capabilities, such as local/regional 211 systems, county service and HIOs.
3. Where possible, align with and leverage peer state and federal best practices for social service data exchange, especially in the adoption and use of data exchange (e.g., FHIR) and security and access standards.
4. Adopt an agile and learning systems approach to this Roadmap as the social services data sharing ecosystem is rapidly evolving at the state and national level. In some cases, this may mean starting with data access as we move to electronic exchange.
5. Incorporate health equity by design from the beginning, throughout design, build, and implementation. Build with and for a diversity of users and focus on solving problems that are meaningful for consumers.

Landscape

Summary of Current State

Social Services in California

In California, social services span beyond state or federal government-funded programs and are often administered by a range of community-based organizations (CBOs) and non-profit organizations (see examples in Table 2).

Table 2. Examples of Social Services Offered in California

Oversight	Service/Program	Description
California Department of Public Health (CDPH)	Women, Infants and Children (WIC)	Services provided through Local WIC Agencies, county health departments, community health centers, and community-based non-profit organizations. ¹⁴
California Department of	Foster Care Services	Administered by county child welfare agencies that provide administration and case management of children in the foster care system.

¹⁴ California Department of Public Health. “Woman Infants, and Children (WIC), Local Agencies.” Accessed October 23, 2024. <https://www.cdph.ca.gov/Programs/CFH/DWICSN/Pages/LocalAgencies.aspx>.

Social Services (CDSS)		
Department of Health Care Services (DHCS)	Behavioral Health Bridge Housing Program	Provides funding to county Behavioral Health Agencies , who often contract with a range of CBOs and mental health providers to provide temporary, safe housing and essential support for people transitioning from homelessness to permanent housing. ¹⁵

There is also a wide range of longstanding community-based systems, some with their own social service data exchange capabilities (mostly with their participating service providers), including, for example—

California 2-1-1: Free telephone service operated by county-based entities to connect Californians to local community services. Regional 2-1-1 service providers establish and maintain a database of available services and relevant programs/agencies.¹⁶

Homeless Management Information System (HMIS): The U.S. Department of Housing and Urban Development (HUD) oversees 44 Continuums of Care (CoC) in California charged with assisting individuals and families experiencing homelessness. Each CoC is responsible for maintaining an HMIS, which is a local information system used to collect individual-level data on the provision of housing support services to individuals and families at risk of experiencing homelessness.¹⁷

These systems have been designed for different purposes such as program and financial accountability, local community benefit, service navigation, and care coordination for specific populations. Due to these differences, community systems have historically lacked the ability to interoperate effectively, thereby limiting their capacity to provide a comprehensive understanding of member needs.

Investments in Whole Person Care

California has made significant investments to advancing whole person care, particularly through DHCS. For example:

- Through the CalAIM initiative, DHCS began offering **Enhanced Care Management (ECM) and Community Supports** services which integrate both clinical and non-clinical elements of care for high-need Med-Cal Members and offers cost-effective alternatives to traditional Medi-Cal services. DHCS also created the **Providing Access and Transforming Health (PATH) program** a five-year, \$1.85 billion initiative to build up the capacity and infrastructure of on-the-ground partners, such as CBOs, hospitals, county agencies, tribes, and others. These participants are a part of the Medi-Cal delivery system, administered through managed care plans (MCPs), working to implement [Enhanced Care Management and Community Supports](#) and [Justice Involved](#) services under [CalAIM](#). DHCS will build on CalAIM and further expand access to behavioral

¹⁵ Behavioral Health Bridge Housing. “County Behavioral Health Agencies.” Accessed October 23, 2024. <https://bridgehousing.buildingcalhhs.com/county-behavioral-health-agencies/>.

¹⁶ California Public Utilities Commission. “2-1-1 Information Services.” Accessed October 23, 2024. <https://www.cpuc.ca.gov/industries-and-topics/internet-and-phone/211-information-services>.

¹⁷ HMIS: Homeless Management Information System- HUD Exchange. “Homeless Management Information System.” Accessed October 23, 2024. <https://www.hudexchange.info/programs/hmis/>.

health programs through the **Behavioral Health Transformation** initiative which implements Proposition 1.¹⁸

- DHCS executed a data sharing agreement that enables partner agencies—CDPH and DSS—to share member-level eligibility and enrollment data across WIC, CalFRESH (California’s version of the federal Supplemental Nutrition Assistance Program/SNAP), and Medi-Cal to maximize enrollment across these critical public programs. DHCS is supporting MCPs by developing rosters of Medi-Cal members likely-eligible but not yet enrolled in CalFRESH and WIC and providing those rosters to MCPs to conduct outreach.
- DHCS also proposed a local **WIC data sharing pilot program** that aims to maximize enrollment of eligible Medi-Cal children and families into CalFRESH and/or WIC through data sharing, targeted outreach, and improved coordination between MCPs and county agencies.

In addition to the DxF and to aid in the implementation of whole person care initiatives, the state has also developed related guidance around the sharing of health information, including:

- **State Health Information Guidance (SHIG)** created by CDII to clarify federal and state laws that affect disclosure and sharing of health information.
- **Data Sharing Authorization Guidance (DSAG)** and its accompanying toolkits offer guidance around data privacy and sharing consent laws, regulations, and legal protections for individuals and organizations involved in delivering or overseeing health and social services to Medi-Cal members.

While these initiatives have made significant strides to further whole person care for the state’s Medi-Cal population, social service data sharing in California is still in early stages; even with DHCS data sharing contracting requirements with Medi-Cal plans. In addition, local data sharing efforts have not scaled broadly and are challenged with delivering timely information at points of service or contact with clients.

Problem Definition, Issue Identification and Critical Challenges

One of the guiding principles of the DxF is to support whole person care through data sharing across health and human service providers to address care needs and health equity. However, many counties and CBOs that deliver social services lack the infrastructure and resources required to fully participate in the DxF. While the state grapples with disparate health care IT systems lacking interoperability and adherence to uniform data standards, the broader range of IT use of any kind across social service providers adds another set of challenges. Due to the sensitivity of these data, there is also apprehension from stakeholders to release and share this information without clear insight into who will receive the information and how it will be used.

The lack of comprehensive social service data sharing also imposes a significant burden on individuals and families and the system writ large. Individuals and family and referring providers members often lack access to information about the availability of both health and social services, their eligibility criteria, and how they can navigate and access services. And the information systems that support eligibility and enrollment typically do not share information, resulting in duplicative application processes that impede

¹⁸ [Proposition 1](#), a ballot initiative approved in 2024, aims to broaden the behavioral health continuum by offering targeted care to individuals with mental health conditions and substance use disorders, especially focusing on those who are most severely affected, vulnerable, or homeless.

enrollment and create inefficiencies. This is true both for social services and health coverage/benefits. A consistent method and approach that supports the sharing person-level information across disparate programs and systems would help overcome some of these challenges.

Finally, for some types of social service data exchange, an individual or their authorized representative – such as a parent or guardian – must provide their consent before specific information can be shared. Similarly, the sharing of health information between entities covered by the Health Insurance Portability and Accountability Act (HIPAA) and non-covered entities requires consent. California, like all other states, lacks a consistent framework and infrastructure to support a scalable consent management architecture.

Recommendations

Many efforts are underway to share health and social services information, often driven by CalAIM initiatives, and other state, county and local priorities. Without a centralized, statewide health data sharing architecture, the expansion of social service data sharing must include and support existing data sharing capabilities and initiatives across domains including housing, 2-1-1 services, criminal/legal, and other domains. To enable more interoperable exchange of social services data across disparate systems and capabilities, the DxF Roadmap will establish standards, guidance, and policies describing how social service information can be exchanged at scale. In addition, DxF will pursue efforts to determine if and how CalHHS Departments and programs can better support local data sharing aligned with cross-cutting programmatic goals.

Most importantly, DxF will begin 2025 with a set of hypotheses on how it can support scalable social and health data exchange across California. These will be vetted through a range of public fora for stakeholder input, pressure tested with existing implementations and help launch specific use case pilots of new data sharing over the next three years. Creating a system that will scale will take time, and efforts are already underway in support of CalAIM, but the intent of DxF is to go beyond Medi-Cal members and provide a structure that can serve all Californians.

In 2024, CDSS/CDII convened program leaders to develop an affirmative vision for the role of social services and health data to support connection to available services and benefits in relation to three priority life events for Californians:

- Having a Child and Early Childhood;
- Preventing Involvement and Supporting Families Involved with the Child Welfare System; and
- Preventing and Interrupting Homelessness.

Over the next three years, CDII will work with program leaders to develop data sharing guidance and minimum standards to support locally driven use cases beginning with these priority areas. The implementation of this guidance will provide a foundation for developing key resources that can be iterated upon to support broader social services data exchange.

Regulations, Policies and Guidance

1. **Establish Social Service Data Exchange Guidance for specified priority areas.** CDII will assess existing social service data sharing requirements to identify barriers that could hinder data sharing across various programs. For example, for the *Having a Child and Early Childhood* priority area, this may involve identifying data sharing barriers between federal programs (e.g., SNAP and WIC) and

Medicaid benefits for maternity care. To address barriers in program interactions, CDII will develop guidance around navigating potential legal barriers and ensuring interoperability between diverse data systems. Based on adoption and participant feedback, CDII will determine the appropriateness and timing of DxP P&P development to support social service data exchange.

Technical Infrastructure, Architecture and Standards

1. **Establish Standards for Social Service Data Exchange.** CDII will develop minimum viable data sets, including nomenclatures, coding (e.g., use LOINC/HCPCS) that support use case transactions and leverage existing data sharing agreements and standards. These include:
 - **Developing Minimum Viable Data Sets.** Identifying a minimally viable set of social services data elements (including metadata), data definitions, and recommended requirements for exchanging this information (e.g., frequency and quality). These would initially be based on existing data exchange efforts or developed in response to early implementation use cases. The intent is to start with what can currently be operationalized and iteratively be expanded upon. For example, for the *Preventing and Interrupting Homelessness* priority area, this might address data elements from HUD HMIS systems on homeless service engagement and housing status, as well as Medi-Cal plan assignment and CalAIM ECM eligibility. Where relevant, DxP would work with other standard setting bodies (e.g., the HL7 Gravity Project) to expand libraries as needed and continually align with national data interoperability efforts.
 - **Outlining System Capabilities** needed to enable effective data sharing between health plans, health care providers, city and county governments, CBOs, and other entities. These capabilities include: the ability to capture and store data from multiple sources with appropriate metadata and data quality, expectations for data normalization, data security and privacy including user management, interoperability capabilities (e.g., compliance with standards and secure connections), and system performance (e.g., scalability and response times).
2. **Create a vision for how social and health data exchange can connect and scale across California's patchwork system.** Noting that the current system includes community information exchanges, HIOs, enterprise exchanges (within a provider network, including counties) using expanded EHR and population health tools, niche private vendors such as closed loop referral systems and modernized social service data systems in California.

Financing, Contracting and Operations [Data Infrastructure]

1. **Identify State and Federal Funding Sources** to support local social services data exchange capacity. This includes exploring potential capacity-building grants from both government agencies and private organizations that can enhance the development and implementation of data sharing infrastructure, particularly for smaller community-based organizations (e.g., DHCS [PATH](#) program grants).

Cross-Pillar Dependencies and CalHHS' Direct IT Role in Enabling Social/Health Data Sharing

1. **Establish Scalable Identity and Consent Management Capabilities** (*See Consent and Identity Management Pillar*). Effective information sharing about individuals and families requires accurate identity matching. CalHHS will explore and support establishing scalable and sharable identity and consent management services. These services can enable widespread, dynamic, authorized sharing of protected social service information, accurately documented and attributed to the right individual.

Actionable Steps

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
<p>Provide Social Service Data Exchange Resources and Guidance</p>	<ul style="list-style-type: none"> • Develop early implementation plans to address data sharing needs based on initial priority use case areas. • Based on initial priority area use cases, catalogue discrepancies between existing regulations and the data sharing needs of organizations involved in the provision of social services to identify areas where regulations may be overly restrictive or not aligned with current data sharing practices. 	<p>Continually work to address regulatory barriers to enable the exchange of minimally viable data. This may include work at the federal level in alignment with ASTP/ONC with social service programs and their IT vendors.</p>	<p>If appropriate, develop social service data exchange technical requirements Policies and Procedures.</p>

Technical Infrastructure, Architecture, and Standards	CY 2025	CY 2026	CY 2027
Establish Standards for Social Service Data Exchange	Work with stakeholders to develop and release minimum standards for priority social services data exchange areas including: 1) a set of minimum data elements and 2) technical specifications for these elements in accordance with emerging standards from Gravity/FHIR and aligned with other social care IT systems where applicable.	Test standards through pilot use cases; catalogue identified learnings/constraints to data sharing; update guidance.	If appropriate, develop social service data exchange technical requirements for specified use cases.
Define a vision for developing statewide capabilities for social and health data exchange	<ul style="list-style-type: none"> • Work with technical advisors with knowledge of existing system capabilities to identify key stepping stones towards an effective social services data sharing design for California. 	<ul style="list-style-type: none"> • Expand and refine the social service data exchange vision and where appropriate, provide guidance to support the implementation of system capabilities to achieve this vision. 	If appropriate, develop and release P&Ps to support adoption of system capability requirements.

<i>Financing, Contracting, and Operations</i>	CY 2025	CY 2026	CY 2027
<p>Identify State and Federal Funding Sources</p>	<ul style="list-style-type: none"> • Identify existing funding sources that support data systems and sharing to uncover potential redundancies and opportunities to streamline and align efforts; • Complete gap assessment of social service provider (county and CBO) capacity to support social service data exchange 	<ul style="list-style-type: none"> • Based on learnings from the gap assessment, outline available state and federal funding sources to support data sharing 	

DRAFT

Pillar #3: Consent and Identity Management

Introduction

Background of Issues

The exchange of physical, behavioral, and other HSSI is essential to support whole person care. For this exchange to occur, individual consent is required before some types of HSSI can be shared.¹⁹ Under HIPAA, most protected health information (PHI) can be shared for the purposes of treatment, payment, or health care operations (TPO) without requiring an individual's consent. However, federal and state laws prohibit some forms of HSSI to be shared without consent, including certain SUDs that falls under 42 C.F.R. Part 2.²⁰

While many organizations collect individual consent to share certain HSSI, this consent is often limited to specific programs or services rather than to enable broader data exchange across multiple health and social service organizations. Sharing information that requires consent is highly complex; it involves managing individual consent preferences across multiple organizations which are subject to strict federal and state privacy laws. This process requires policies, guidance and controls that both promote information exchange and comply with federal and state rules governing consent. The liability and potential legal repercussions associated with policy violations or unauthorized release of this information create real and perceived barriers for organizations that participate in the exchange of protected information.

Additionally, few organizations treat changes to an individual's consent preferences as event notifications. Without standardized Policies and Procedures to notify health and social service organizations of an individual's modifications or revocations of consent, privacy risks increase, as records and information sharing practices may not reflect the individual's most current consent preferences.

Consent management services can address these challenges by providing policies, guidance, and education that enable individuals to provide, modify and revoke their consent, while ensuring that those serving them respect and follow their preferences. To do this, consent must be "meaningful". According to ASTP/ONC, "meaningful consent" occurs when an individual makes an informed decision, and that decision is properly recorded and maintained.²¹ Meaningful consent requires individuals to be informed about the **purpose** of sharing their information; **who** their information might be shared with; the **type of information** that might be shared; and their **individual rights** to provide, modify and revoke their consent. A consent management strategy must therefore consider how to inform and educate both individuals and the organizations requesting their consent.

Consent management services can also address these challenges by providing technical solutions and architectures to manage the process of providing, modifying, revoking, and communicating consent preferences across multiple organizations that share protected information. To be effective, these services need to be able to resolve an individual's identity; assuring both individuals and service providers that the consent applies to the correct person. The CalHHS Strategy for Digital Identities

¹⁹ U.S. Department of Health and Human Services. Standards for Privacy of Individually Identifiable Health Information. 45 CFR § 164.506 (2013).

²⁰ U.S. Department of Health and Human Services, *Confidentiality of Substance Use Disorder Patient Records*, 42 C.F.R. Part 2 (2013).

²¹ Office of the National Coordinator for Health Information Technology, "Meaningful Consent Overview," September 19, 2018. <https://www.healthit.gov/topic/meaningful-consent-overview>

describes the attributes to be used by DxF Participants to match identities of individuals within different systems and care settings.²² Managing identities is crucial for accurately linking consents to an individual's information, enabling the appropriate sharing of information about that individual across health and social service providers.

Goal

The goal of the DxF Roadmap Consent and Identity Management Pillar is to develop a statewide consent and digital identity management framework that allows individuals to provide, update, and revoke their consent to share protected Health and Social Service Information (HSSI) between their care and social service partners.

Central Tenets

The following tenets will guide the development of this Pillar's recommendations.

1. Empower individuals to control whether and how their protected HSSI is shared by ensuring consent management systems are accessible and support meaningful consent.
2. Improve individual outcomes by ensuring appropriate data exchange between health and social service providers through coordinated consent management and identity management processes.
3. Establish, standardize, coordinate, and streamline consent management and identity management processes without interrupting existing community data exchange capabilities and local trusted relationships with social service providers.
4. Minimize the burden that individuals, providers and other institutions face to authorize, access, and manage consent.
5. Design for large-scale implementation that leverages locally driven health and social exchanges. The system should be adaptable to the needs of local organizations while being robust enough to support widespread adoption and evolving interoperability standards.

Landscape

Summary of Current State

California's consent management landscape is complex and fragmented. Organizations and individuals face challenges navigating complex rules and the various consent forms that may be used in jurisdictions to enable the exchange of protected HSSI.

For example, behavioral health providers often struggle to interpret and adhere to privacy regulations governing SUD data, as outlined in 42 C.F.R. Part 2. This complexity leads many providers to default to not sharing SUD data with other organizations, even when it is legally permissible and could support better care coordination.

Moreover, consent management practices vary, with different systems in place across health and social service providers, including paper forms, as well as electronic systems such as EHRs, HIOs, and Community Information Exchanges (CIEs). Most QHIOs across the state do not currently have consent

²² California Health and Human Services Agency. "CalHHS Digital Identity Framework Strategy." January 2023. <https://www.cdii.ca.gov/wp-content/uploads/2023/01/CalHHS-DxF-Strategy-for-Digital-Identities-FINAL.pdf>.

management capabilities, relying instead on providers and other organizations to manage consent processes.

Over the years, CalHHS, DHCS, and other state departments have developed guidance to help organizations comply with federal and state regulations around data privacy and sharing. CalHHS developed the State Health Information Guidance (SHIG)²³, which describes when certain HSSI can be exchanged, and provides clarity on state and federal privacy laws. In 2023, DHCS released the CalAIM Data Sharing Authorization Guidance (DSAG)²⁴ to provide guidance to Medi-Cal Partners²⁵ who are providing or overseeing the delivery of health or social services to members. To complement the DSAG and SHIG, DHCS began developing DSAG Toolkits in 2024 to illustrate real world scenarios that help Medi-Cal Partners navigate data privacy and data sharing regulations related to CalAIM, including Assembly Bill 133 and the C.F.R. Part 2 Final Rule. The initial focus of these toolkits includes the Reentry Initiative, Medi-Cal Housing Support Services, and programs for Children and Youth. DHCS plans to make these toolkits available in 2025.

Additionally, DHCS piloted the Authorization to Share Confidential Medi-Cal Information (ASCFI) tools²⁶ in 2023 in San Diego, San Joaquin, and Santa Cruz counties to facilitate the exchange of protected HSSI about Medi-Cal Members. The ASCFI tools used in the pilot included a standard release of information form and a regional consent management service designed to simplify the process of obtaining and managing consent to share protected Medi-Cal Member data. The ASCFI form enabled Medi-Cal Members to describe their preferences for sharing protected HSSI, which could be shared between counties, health plans, providers and others via contracted HIO(s) and CIEs. This ensured that consent preferences were readily accessible to both the individuals and the health and social services organizations that serve them. The feedback from the pilot was overwhelmingly positive, with both providers and individuals recommending broader implementation of the tools. As such, DHCS is in the process of refining the ASCFI tools, including enhancing the form based on feedback from pilot participants, and considering how they might support statewide consent management services.

Stewards of Change Institute (SOCi) recently published a conceptual model to address challenges in obtaining and managing consent to share information across health and human services. The SOCi white paper outlines various strategies for obtaining informed, voluntary consent from individuals to share their personal, identifiable, sensitive information across service providers, including the ASCFI tools as an example, to deliver whole person care.²⁷ The California Health Care Foundation (CHCF) also published a paper outlining the key components necessary to scale statewide consent services and

²³ Center for Data Insights and Innovation, "State Health Information Guidance (SHIG)," April 2023.
<https://www.cdii.ca.gov/compliance-and-policy/state-health-information-guidance-shig/>.

²⁴ California Department of Health Care Services, "CalAIM Data Sharing Authorization Guidance," October 2023.
<https://www.dhcs.ca.gov/CalAIM/ECM/Documents/CalAIM-Data-Sharing-Authorization-Guidance.pdf>.

²⁵ Medi-Cal Partner refers to any person or organization that provides Medi-Cal reimbursable health and social services to Members is a Medi-Cal Partner. This includes, but is not limited to, Medi-Cal MCPs, Tribal Health Programs, health care providers, community-based social and human services organizations and providers, local health jurisdictions, correctional facility health care providers, and county and other public agencies that provide services and manage care for individuals enrolled in Medi-Cal.

²⁶ California Department of Health Care Services, "ASCFI CalAIM," 2023,
<https://www.dhcs.ca.gov/CalAIM/Pages/ASCFI-CalAIM.aspx>

²⁷ Stewards of Change Institute, "Catalyzing Whole-Person Care: Consent-to-Share is the Key", September 23, 2024.
https://stewardsofchange.org/wp-content/uploads/sites/2/2024/09/SOCI_report.pdf.

implement a robust digital identity strategy.²⁸ By expanding the use of the ASCMI tools and learning from other models and experiences, California can establish scalable, centralized statewide consent management services that can be used by individuals, counties, managed care plans, providers, health systems, Community-based organizations, and other government agencies.

At the federal level, several standards, specifications, and application programming interfaces (APIs) have been developed to support consent management including:

- *Trusted Exchange Framework and Common Agreement (TEFCA)*: Sets national standards for secure health information exchange between health information networks. The Common Agreement Version 2.0 released in April 2024, includes consent management requirements such as standardized processes for obtaining and managing individual consent for data sharing. The Common Agreement also includes requirements for written Policies and Procedures to allow an individual to change or revoke their consent on a prospective basis.²⁹
- *Health Level Seven (HL7) Composite Privacy Consent Directive—domain analysis model*: Harmonizes security and privacy requirements in Health care, aligning with international securities standards. The model focuses on implementing controls to enforce privacy policies, consent directives and access standards across EHRs.³⁰
- *HL7 Healthcare Privacy and Security Classification System, Release 1*: Outlines standards for automated labeling and segmentation of PHI, enabling Health care organizations to manage patient consent and ensure that only authorized users can access protected data.³¹
- *HL7 Services Functional Model: Consent Management Service, Release 1*: Outlines standards on APIs for managing patient consent, enabling Health care organizations to integrate consent management services into their systems.³²
- *HL7 Clinical Document Architecture (CDA) R2 Implementation Guide: Privacy Consent Directives, Release 1*: Outlines standards on exchanging signed consent directives, enabling Health care organizations to manage and enforce computable privacy consents across EHR systems while supporting multiple representations (e.g., narrative, signed and computable formats).³³

²⁸ California Health Care Foundation. *Consent to Share: California's Approach to Cross-Sector Data Sharing*. October 2023. <https://www.chcf.org/wp-content/uploads/2023/10/ConsentToShareCACrossSectorDataSharing.pdf>.

²⁹ Office of the National Coordinator for Health Information Technology (ONC). "Trusted Exchange Framework and Common Agreement (TEFCA)." August 1, 2024. <https://www.healthit.gov/topic/interoperability/policy/trusted-exchange-framework-and-common-agreement-tefca>.

³⁰ Health Level Seven International (HL7). "HL7 Version 3 Domain Analysis Model: Composite Security and Privacy, Release 1," May 1, 2014. https://www.hl7.org/v3ballotarchive/v3ballot/html/dams/uvsec/V3DAM_SECURITY_R1_I1_2014MAY.pdf.

³¹ Health Level Seven International (HL7). "HL7 Healthcare Privacy and Security Classification System (HCS), Release 1" August 8, 2014. https://www.hl7.org/implement/standards/product_brief.cfm?product_id=345.

³² Health Level Seven International (HL7). "HL7 Services Functional Model: Consent Management Service, Release 1," July 13, 2021. https://www.hl7.org/implement/standards/product_brief.cfm?product_id=571.

³³ Health Level Seven International (HL7). "HL7 CDA® R2 Implementation Guide: Privacy Consent Directives, Release 1," December 9, 2021. https://www.hl7.org/implement/standards/product_brief.cfm?product_id=280.

- *HL7 Fast Health care Interoperability Resource (FHIR) Consent Resource*: Outlines a standard data model to represent and manage a patient's consent regarding the use, sharing and disclosure of their Health care information.³⁴
- *Integrating the Health care Enterprise (IHE) Basic Patient Privacy Consents*: Outlines standards for health care systems to record and enforce patient privacy consents, allowing flexibility in who can access health information based on the patient's consent.³⁵
- *IHE Privacy Consent on FHIR*: Outlines standards for patient privacy consents and access control where a FHIR API is used to access document sharing health information exchanges.³⁶

As the DxF continues to refine the framework for consent management, these federal standards provide a foundation for the development of interoperable, secure systems that safeguard patient privacy while promoting data sharing.

Problem Definition, Issue Identification and Critical Challenges

Several consent management challenges create barriers to effective data exchange and care coordination. Among these challenges are legal and regulatory complexities leading to cultural resistance to data sharing; resource constraints, technical limitations; and identity management gaps. These barriers are particularly acute for smaller organizations that often lack the financial and technical resources to fully participate in the exchange of HSSI.

Legal and Regulatory Complexities

The sharing of HSSI is governed by a complex and extensive set of federal and state rules which are subject to varying interpretations. This makes it challenging to develop consent management policies that satisfy all parties; especially when it pertains to rules governing the sharing of SUD treatment information. The complexity of regulatory frameworks surrounding the exchange of protected HSSI, creates uncertainty and perceived risks for organizations who maintain it. This often leads to organizational siloes, where institutions elect not to share information due to internal policies, privacy concerns, or cultural resistance.

Resource and Technological Limitations

Many organizations that maintain protected HSSI lack robust information technology systems and need access to additional tools and services to participate in bidirectional data exchange. Many EHRs, care management, and other electronic documentation systems lack the capability to store, manage, and track individual consent preferences. Additionally, most HIO(s), CIEs, EHRs, and other care management platforms are not equipped to handle the complex consent rules and requirements needed to enable seamless and automated exchange of protected HSSI. This technical hurdle is compounded by the absence of a universal consent form, which leads to inconsistencies in tracking and managing consent

³⁴ HL7 Fast Healthcare Interoperability Resource (FHIR), "Resource Consent - Content," March 26, 2023.
<https://www.hl7.org/fhir/consent.html>

³⁵ Integrating the Healthcare Enterprise (IHE). "Basic Patient Privacy Consents (BPPC)" August 4, 2023.
<https://profiles.ihe.net/ITI/TF/Volume1/ch-19.html>.

³⁶ Integrating the Healthcare Enterprise (IHE). "Privacy Consent on FHIR " February 23, 2024.
<https://profiles.ihe.net/ITI/PCF/>.

across different organizations, systems, and regions. These technical challenges limit sharing of consent preferences across organizations, resulting in information siloes and uncoordinated care.

Identity Management Gaps

Finally, identity management challenges add a layer of complexity to consent management. Identity management includes multiple components: matching individual identifiers across systems, granting individuals access to systems to manage their consent, and assuring an individual's identity. Without reliable mechanisms for identity management across different systems, it is difficult to accurately link individuals with their consents, limiting providers from accurately seeing if and when an individual has consented to sharing their protected HSSI.

Recommendations

The proposed approach supports the development of a scalable consent management architecture, along with a set of services, policies and guidance to support statewide implementation of consent and identity management services. This strategy will incorporate feedback from stakeholders, including counties and health and social services providers.

Regulations, Policies, and Guidance

Establish use cases, guidance, and strategies to support implementation of statewide, centralized or federated consent and identity management services.

1. **Establish DxF consent management use cases** that align with CalHHS whole person care priorities. The use cases should build upon those developed by DHCS and other departments to define policies, technologies, processes, and dataflows needed to support the management of meaningful consent and exchange of protected HSSI by health and social service organizations.
2. **Develop toolkits** that complement those being developed by DHCS. Toolkits will depict real-world data sharing and consent management scenarios, answering frequently asked questions, and providing practical guidance to those on the ground implementing consent management processes. Data sharing toolkits should focus on priority use cases, including, but not necessarily limited to:
 - a. Linking individuals who are unhoused or are at-risk of becoming unhoused to health and social services that can support their health and social needs.
 - b. Facilitating the sharing of SUD treatment data between C.F.R. Part 2 and non-C.F.R. Part 2 entities.
 - c. Improving care coordination and health insurance eligibility determination and enrollment for individuals involved in the criminal legal system.
 - d. Supporting individuals and families involved with the child welfare system.

Additional toolkits may be added to include connecting individuals to WIC, SNAP, and other program benefits, and facilitating the sharing of data for children and youth services in schools.

3. **Establish DxF consent management policies and procedures** that promote consent management services and architecture. This may include leveraging QHIOs and specifying their role in consent management to realize an efficient, scalable architecture.
4. **Create an education and outreach campaign** to focus on increasing awareness, understanding, and benefits of consent management processes among individuals, providers, counties, and other stakeholders. This will require coordinating with DHCS, CDSS and other CalHHS departments to

support training and technical assistance for organizations to effectively implement and utilize consent management services. It will also provide guidance to ensure individuals are fully informed of their rights and consent management processes.

5. **Develop a scalable consent and identity management strategy** that builds upon DHCS' work to support Medi-Cal Members and providers, while expanding the scope of eConsent services to encompass all health and social service organizations in California. The strategy may include collaborating with the Office of Technology and Solutions Integration (OTSI), the California Department of Technology (CDT), and other agencies to support scalable identity management services. It will also include considerations for ongoing management, governance and sustainability of statewide consent and identity management services.

Technical Infrastructure, Architecture, and Standards

Leveraging DHCS's ASCMI eConsent service initiatives to establish a scalable architecture that support statewide implementation of consent and identity management services.

1. **Establish an architecture for consent and identity management** services that aligns with DHCS's work to advance the ASCMI eConsent concept. The architecture will explore centralized and coordinated federated services that provide individuals with access to consent and identity management services; allowing individuals to provide, modify, and revoke their consent. It will consider centralized and federated storage and management of individual identities and consent management preferences, while also supporting an architecture that allows QHIOs and potentially other intermediaries to link identities to support data exchange. The architecture should include notification capabilities that provide updates to individual consent preferences, changes in Medi-Cal status, expired consent, and other events.
2. **Require use of national standards**, which may include HL7 classifications, implementation guides, FHIR resources, TEFCAs, and other emerging federal standards through amendments of DxP Policies and Procedures.
3. **Support local implementation** through regional health and social service information exchange organizations that build upon existing local initiatives. And technical assistance that supports adoption of centralized or federated services by intermediaries.

Financing, Contracting, and Operations

Leverage state and federal funding sources and collaborate with DHCS, CDSS and other departments to launch, incentivize, manage and govern statewide consent and identity management services.

1. **Secure funding for statewide consent and identity management services** that may include capabilities developed by CalHHS, DHCS, CDSS and other state departments and agencies. This may include supporting the development of a DHCS Advance Planning Document (APD) FFP request and identifying additional funding to support expansion beyond Medi-Cal Members and providers. Funding should be used to support implementation, onboarding, ongoing management and sustainability of consent and identity management services, and technical assistance, training, and education campaigns.

2. **Explore models for implementing and operating centralized or coordinated federated consent and identity management services** by CalHHS, DHCS, CDSS, and other Departments, agencies and vendors. Explore governance models that provide oversight, policies and assurances that services are managed and maintained in accordance with federal and state rules.
3. **Support identification of vendors** in coordination with DHCS and other departments and stakeholders to support the technical, operational, and governance requirements of centralized services. Use those requirements to support procurement of vendors for statewide identity and consent management services.
4. **Coordinate with departments to incentivize use of the consent management service.** Incentive programs should be established to adopt and use statewide consent and identity management services. Contractual requirements, notices and bulletins, and licensing and certification requirements should be developed and put in place across applicable state agencies that oversee organizations subject to the DxF.

Actionable Steps

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
Consent Management Use Case Development	Draft and publish initial set of consent management use cases.	<ul style="list-style-type: none"> • Update initial use cases. • Draft and publish second set of consent management use cases. 	Update use cases as needed and appropriate.
Guidance and Toolkit Development	<ul style="list-style-type: none"> • Support updates to the SHIG to include additional use cases. • Develop initial set of data sharing guidance toolkits. 	<ul style="list-style-type: none"> • Support updates to the SHIG to include additional use cases. • Develop initial set of data sharing guidance toolkits. 	Update toolkits with second set of use cases.
Policies and Procedures	<ul style="list-style-type: none"> • Develop initial draft Policies and Procedures for consent and identity management, services, aligning requirements with DHCS’s ASCMI eConsent services. • Finalize initial Policies and Procedures for consent and identity management, incorporating stakeholder feedback. 	<ul style="list-style-type: none"> • Develop initial draft Policies and Procedures for consent and identity management, services, aligning requirements with DHCS’s ASCMI eConsent services. • Finalize initial Policies and Procedures for consent and identity management, incorporating stakeholder feedback. 	Potential updates to Policies and Procedures to address additional use cases.

DRAFT FOR PUBLIC COMMENT: Data Exchange Framework Roadmap

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
Education and Outreach	Develop education and outreach campaign to support training and technical assistance for ASCMI consent tools.	Develop education and outreach campaign to support training and technical assistance for ASCMI consent tools.	Develop education and outreach campaign to support training and technical assistance for ASCMI consent tools.

<i>Technical Infrastructure, Architecture, and Standards</i>	CY 2025	CY 2026	CY 2027
Architecture for Consent Management	Coordinate with DHCS, other departments, QHIOs and other stakeholder to develop architectural and business requirements for consent and identity management services.	Partner with DHCS, CDSS and other departments to support implementation of consent and identity management services.	Partner with DHCS, CDSS and other departments to support implementation of consent and identity management services.
National Standards	Develop initial draft DxF consent management standards, aligned to national standards.	Update and publish DxF consent management standards.	Update and publish DxF consent management standards.
Expand ASCMI eConsent Services	<ul style="list-style-type: none"> Identify opportunities to and support engagement with stakeholders in ASCMI tools design. Expand ASCMI eConsent services to select early adopter QHIOs/HIOs/CIEs, county and community partners. 	Begin implementation of ASCMI eConsent services among the early adopter QHIOs.	Implement ASCMI eConsent services among all remaining QHIOs.

<i>Financing, Contracting, and Operations</i>	CY 2025	CY 2026	CY 2027
Secure funding for consent and identity management services	Collaborate with DHCS and other departments to secure state and federal FFP funding for consent management services.	<ul style="list-style-type: none"> • Funds would be provided for services delivered with required associated reporting. • Identify ongoing sustainability model for consent and identity management services. 	<ul style="list-style-type: none"> • Funds would be provided for services delivered with required associated reporting. • Identify ongoing sustainability model for consent and identity management services.
Develop consent and identity management service requirements	Work with DHCS, other departments, QHIOS and other stakeholders to develop requirements for consent and identity management services.	Work with DHCS, other departments, QHIOS and other stakeholders to develop requirements for consent and identity management services.	Work with DHCS, other departments, QHIOS and other stakeholders to develop requirements for consent and identity management services.
Support identification of vendors	Partner with DHCS to identify and procure technical solutions for consent and identity management services.	Partner with DHCS to identify and procure technical solutions for consent and identity management services.	Partner with DHCS to identify and procure technical solutions for consent and identity management services.
Develop incentives	Coordinate with departments on the development of incentive programs (if available), contractual requirements, bulletins, notices, and directives to encourage support of identity and consent management services.	Coordinate with departments on the development of incentive programs (if available), contractual requirements, bulletins, notices, and directives to encourage support of identity and consent management services.	Coordinate with departments on the development of incentive programs (if available), contractual requirements, bulletins, notices, and directives to encourage support of identity and consent management services.

Pillar #4: Public Health

Introduction

Background of Issues

The COVID-19 pandemic revealed significant shortcomings in the country's public health infrastructure, particularly in its outdated and siloed data systems. This gap stems from historic underfunding of public health initiatives, leading to the fragmented and often obsolete IT systems that hinder our ability to respond to emerging threats. While some investments have been made to support IT capabilities of health care providers, such as the 2009 Health Information Technology for Economic and Clinical Health (HITECH) Act, similar investments in public health data systems have lagged behind. Lack of integration between health care and public health IT systems means that data cannot be easily shared between these sectors, hindering efforts to track and respond to public health crises.³⁷

Efforts by the CDC have begun to address these issues, making significant strides in improving data exchange between health care providers and public health agencies (PHAs). Notably, the development and expansion of electronic case reporting (eCR), which automates the submission of case data from health care providers to PHAs, is significantly enhancing the speed and accuracy of public health reporting. Before the pandemic, only a small number of health care facilities were able to send automated reports through eCR. After the onset of the pandemic, tens of thousands began reporting COVID information through eCR; this has since declined, and the expansion to other reportable conditions has been variable.

Despite these advances, much work remains to fully integrate public health with the broader health care IT ecosystem. The CDC, in partnership with ASTP/ONC, are focused on aligning data and system standards across public health and health care. CDC and ASTP/ONC are also continuing to push for and enable standardized application programming interfaces (APIs) for public health purposes to facilitate real-time data exchange for public health. For example, Fast Healthcare Interoperability Resources (FHIR) standards for health care systems, are in the process of being adapted for public health data exchange purposes through initiatives like the HL7 HELIOS FHIR Accelerator and the United States Core Data for Interoperability Plus (USCDI+).^{38,39}

TEFCA is another initiative aimed at breaking down data silos across the country. TEFCA has recently expanded its scope to permit the exchange of information under the framework for public health purposes, authorizing PHAs to access, exchange, and leverage health information for public health

³⁷ Layden, Jennifer E., Matthew J. Swain, Niall Brennan, and Micky Tripathi. "Plugging Public Health Data into the Health IT Ecosystem to Protect National Health." *NEJM Catalyst Innovations in Care Delivery* 5, no. 8 (2024). <https://doi.org/10.1056/CAT.24.0129>.

³⁸ Office of the National Coordinator for Health Information Technology. "USCDI Plus." *HealthIT.gov*. Last reviewed July 26, 2023. <https://www.healthit.gov/topic/interoperability/uscdi-plus>.

³⁹ HL7 International. "Helios FHIR Accelerator for Public Health Home." <https://confluence.hl7.org/display/PH/Helios+FHIR+Accelerator+for+Public+Health+Home>.

through the TEFCA framework.⁴⁰ The CDC and ASTP/ONC are already leveraging TEFCA and the proposed Health Data, Technology, and Interoperability (HTI-2) rule to support public health use cases using national standards.⁴¹ These efforts are early in design and implementation, and the practical data flows are not yet well defined. Exploring the roles and interplay between DxF and TEFCA will be essential to enable statewide public health data exchange.

Goal

The goal of the DxF Roadmap Public Health Pillar is to accelerate the adoption and use of interoperable data systems for public health activities.

Central Tenets

The following tenets will guide the development of this Pillar's recommendations.

1. Align DxF with existing and emerging electronic Public Health data systems.
2. Better define and clarify interactions between interoperability capabilities and standards (TEFCA, CDC, DxF) to enable Participants to exchange public health data at scale.
3. Support CDPH's Data Modernization and Standardization efforts as their ecosystem moves to cloud-based, API-driven data exchange.

Landscape

Summary of Current State

As Federal Agencies continue to integrate public health and health care IT systems, California will need to find ways to meaningfully participate. California's public health data systems are currently distributed across 61 local health jurisdictions (LHJs), each with their own system of record. While 59 of these jurisdictions use California Reportable Disease Information Exchange (CalREDIE) as their system of record for reportable conditions, Los Angeles, San Francisco, and San Diego Counties do not fully participate. While this decentralized structure reflects the unique needs of regions across the state, it presents an opportunity for greater interoperability by leveraging national infrastructures developed and maintained by the CDC. CDII is considering ways it can support public health data exchange efforts through the DxF, and potentially streamline provider connectivity to support a wide range of use cases, starting with EHR interoperability.

State Public Health authorities are also confronting restrictive privacy and confidentiality requirements specific to public health information, limiting the sharing of information. At the national level, HIPAA

⁴⁰ The Sequoia Project. "XP Implementation SOP: Public Health." Last modified August 2024.

<https://rce.sequoiaproject.org/wp-content/uploads/2024/08/XP-Implementation-SOP-Public-Health-PH.pdf>.

⁴¹ Office of the National Coordinator for Health Information Technology. "Health Data, Technology, and Interoperability: Patient Engagement, Information Sharing, and Public Health Interoperability (HTI-2) Proposed Rule." HealthIT.gov. Last reviewed August 22, 2024. <https://www.healthit.gov/topic/laws-regulation-and-policy/health-data-technology-and-interoperability-patient-engagement>.

allows for the disclosure of clinical information without explicit patient consent to Public Health Authorities (PHAs) for public health purposes. However, there are a few uniform national standards for safeguarding data held by state public health agencies, making state laws central to discussions of privacy and security within the public health system. In addition, local health jurisdictions (LHJs) can also impose their own privacy and security requirements, so long as they do not conflict with State and Federal law. This often results in local jurisdictions operating in data silos, despite the potential benefits of a unified, multitenant cloud database for managing data across jurisdictions.

California is actively working to support greater interoperability through the California Department of Public Health's (CDPH) planning and roadmap strategies under Future of Public Health (FoPH) IT and Data Modernization initiatives, largely funded by the CDC. The FoPH initiative emphasizes resilient, adaptable, and equitable public health systems and aims to:

- Highlight the modernization of public health data systems as a foundational Pillar of building resilience in public health infrastructure.
- Ensure that interoperability not only supports crisis response, but also long-term health improvements across under-resourced communities, aligning with the equity goals of FoPH.
- Promote data equity by ensuring all LHJs, regardless of size or funding, can access and benefit from these systems.⁴²

The strategy aims to modernize the state's public health ecosystem and a timely sharing of public health information with LHJs through development of multi-tenant cloud-based systems.⁴³ LHJ public health capabilities (and systems) are supported by a complex and multi-directional flow of funds, including: CDC funds to state and some local health departments, state funds to local health programs, and state/local governments contributing their own funds. This distributed system, as well as program-specific inflexible funding, lead to variations in public health capacity and services across jurisdictions.

CDPH is also leading work to manage statewide data platforms while supporting local public health jurisdictions, such as the statewide immunization registry (CAIR2) and CalREDIE (tools for case report management, surveillance, and electronic lab and case reporting). CDPH intends to upgrade both of these systems to support broader interoperability capabilities. The state now has a direct role in supporting ED connections to the CDC's national syndromic surveillance platform (NSSP BioSense). BioSense is a cloud-based monitoring system that collects and analyzes de-identified data on symptoms from EDs and other sources, helping to detect and respond to potential public health threats.

⁴² California Department of Public Health. "Future of Public Health." Accessed October 21, 2024.
<https://www.cdph.ca.gov/Pages/FoPH/future-of-public-health.aspx>.

⁴³ Shared online database storage where different jurisdictions have their own secure space within the system.

Problem Definition, Issue Identification and Critical Challenges

The existing fragmentation in California's public health data systems and fragmented and inflexible funding structure complicate efforts to standardize data sharing across different public health reporting requirements and systems. The absence of a unified approach and common technical standards is leading to inefficiencies and large public resource demands to draw connections between and make modifications to individualized systems of record. Existing CDC/national infrastructures, such as those related to electronic case reporting and syndromic surveillance, are ripe for broader adoption and can be a starting point.

Opportunities for Resolution

California's public health data systems, while currently siloed, present significant opportunities for enhanced interoperability through the potential roles of DxF and TECA in supporting public health data exchange.

The DxF establishes Policies and Procedures for the exchange of HSSI for DxF Participants across many sectors, some of which may be implicated by a multitude of public health reporting requirements, standards, and electronic data systems that exist outside of the DxF. There is an opportunity for DxF to expand its guidance to incorporate public health standards and technical requirements. Such guidance would support greater ease and efficiency in data sharing and overall promote more comprehensive engagement and adoption of interoperable data systems.

There are also opportunities for DxF to support partnering state and federal PHAs, such as CDC, CDPH and LHJs, in advancing interoperable exchange through discrete public health use cases. For instance, DxF could play a role in streamlining electronic case reporting and follow-up investigations or aligning with ED syndromic surveillance reporting requirements. Successfully addressing these use cases will require clear definitions of QHIO (DxF) versus QHIN (TECA) roles in effectively supporting specific public health functions. While the most common challenges cited are resources needed for new systems, modifications, and connections, an overall move to common ontologies, languages and API exchange could yield significant economies of scale and effort. Use cases will need to address any state and/or local data sharing constraints as they apply to public health.

Scenarios/Use-Cases

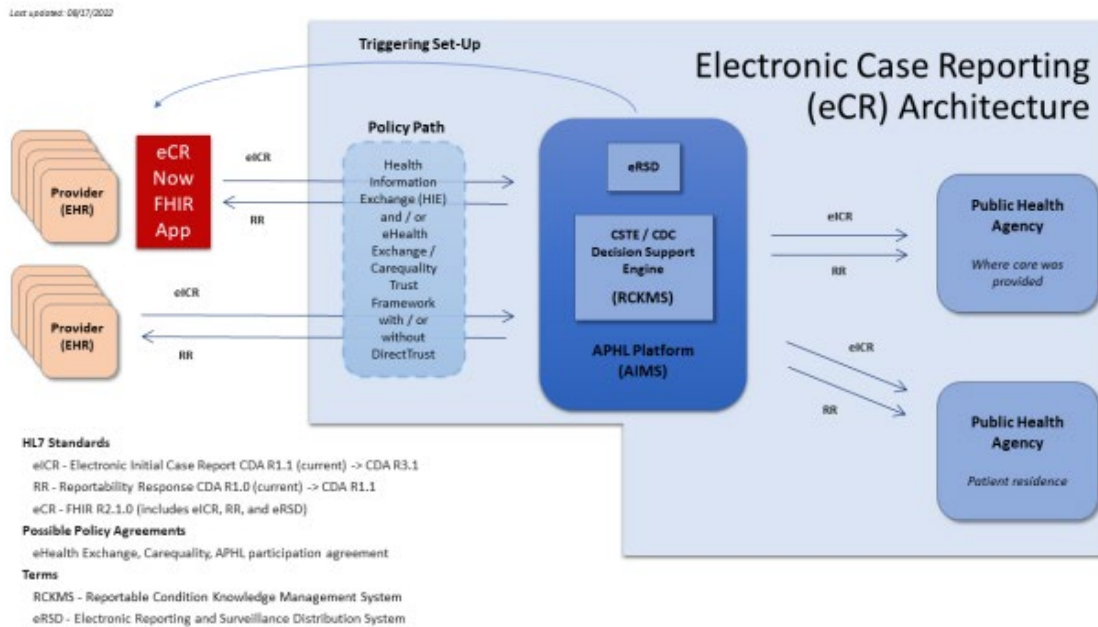
1) Implementation of eICR through TECA

ECR is the automated, near real-time generation and transmission of case reports from EHRs to PHAs for review and action.⁴⁴ Health care providers are required by law in all U.S. states and territories to report diseases and conditions of interest to public health. The eCR platform, the Association of Public Health Laboratories' (APHL) Informatics Messaging Services, or AIMS, directly connects to clinical providers via their EHRs and electronically flows case reporting information to California public health entities. In some cases, data flows directly to an LHJ (such as Los Angeles County) and for other jurisdictions the

⁴⁴ Centers for Disease Control and Prevention. "Electronic Case Reporting (eCR)." Accessed October 21, 2024. <https://www.cdc.gov/ecr/php/index.html>.

data flows through the CalREDIE platform to the LHJs. CDPH maintains the direct connection between AIMS and CalREDIE. CDC's eCR team, in coordination with APHL and the Council of State and Territorial Epidemiologists, provides support for eCR implementers, with state or local PHAs responsible for setting data reporting requirements and assuring data quality for reporting purposes.

Figure 3. Electronic Case Reporting Architecture via APHL Informatics Messaging Services (AIMS)



From: <https://ecr.aimsplatform.org/cms/resources/blocks/introduction-to-electronic-case-reportingfor-ehr-and-health-it-vendors.pdf>

The electronic initial case report, or eICR, is triggered locally in the EHR system and sent to the AIMS platform. In some circumstances, the eICR will be all that is needed to support public health reporting. Having electronic case reports on reportable conditions sent from EHRs and received by PHAs represents a significant accomplishment of interoperability between health care and public health. The eICR may lead to the reporting of additional data or follow-up by the PHA to: confirm reportability; provide condition-specific or public health jurisdiction-specific case data; and/or support public health investigation, contact tracing, and/or countermeasure administration. The eICR is a Health Level Seven International (HL7) Clinical Document Architecture (CDA) balloted standard for reporting to public health.

One of the challenges noted by larger health care delivery systems that operate across geographies in California has been slightly different eICR reporting requirements by LHJs. This makes implementation more difficult, especially when adjustments need to be made by the EHR vendor in response. As part of the move to a national trusted framework (TEFCA) for data exchange, ASTP/ONC has been working with the CDC to further modernize eCR and align with emerging FHIR data standards. The Kaiser Permanente system in California manages 30% of commercially covered lives in California and is an early adopter of the TEFCA framework. Together with their EHR vendor and its associated QHIN, they plan to implement eICR via TEFCA in California and further determine whether TEFCA can support the additional data

information needs required for some reportable conditions. Similarly, DxF may provide the permissions and mechanism for public health queries and responses for that information.

As part of California's early implementation, CDPH will work to align consistent clinical data element requirements by reportable condition across LHJs and also centralize effort at the state CDPH level rather than requiring effort with each LHJ across the state to support AIMS connectivity (efficiency + scale). This early implementation will also provide a glide path for broader eICR adoption across other Epic QHIN participants in California.

What We Will Learn

The DxF Data Sharing Agreement (DSA) and the TEFCA Common Agreement, while meant to be inclusive of public health use cases, were not specifically designed to support them. Early implementation will clarify if/how TEFCA can support LHJs in case reporting and management. It is unclear, for example, whether LHJs and/or CDPH will need to sign a TEFCA Common Agreement and, if so, whether as a participant or sub participant.

Early implementation will help determine: whether LHJs can and should sign the DxF DSA for query/response access to clinical records, whether their DxF conditions of participation should differ from other DxF Participants, whether LHJ systems of record should be a part of this ecosystem, and further clarify how DxF aligns with CDC-funded CDPH and LHJ data modernization efforts and timelines.

2) Syndromic Surveillance Supported by DxF

Alignment across DxF event notification requirements and ED syndromic surveillance reporting may markedly enhance participation given the common need for acute hospital ED ADT connectivity and strategies to assure statewide coverage and ability to route alerts across DxF Participants.

This use case differs in several key ways from other person-centered data exchanges. First, data reported to a national system is de-identified. Second, data sharing and reporting follows an HL7 message standard which is currently not a part of DxF event alert requirements. Third, given that DxF is now defining data flows to support event notifications, it is unclear whether this use case can and should be incorporated into the DxF.

What needs to be done

California is at an inflection point with its syndromic surveillance program—the recent passage of SB159, Chapter 40, Statutes of 2024, activates a direct role for CDPH (prior, engagement in syndromic surveillance was mediated by LHJs).

Further investigation is needed to determine what, if any, actionable steps can be taken by DxF in support of this use case. CDII and CDPH intend to delve further into understanding how the two programs might interact and ideally whether we can simplify engagement in both programs for acute care hospital EDs. The intent is to have a clear sense of actionable steps (if any) by Q2 2025.

Over the next three years, the CDC and ASTP/ONC will continue to generate joint use cases and initiatives using electronic data exchange to promote public health. These initiatives are developing in rapid succession and will drive DxF public health roadmap efforts in the next three years. Ideally, California will participate in early implementations, as well as help drive interoperability standard development and adoption aligned with federal priorities and investments.

Recommendations

DxF Guidance to Support Public Health Use Cases

Based on experience from the eICR implementation via the TEFCA framework, the DxF should clarify how LHJs can access additional information electronically after receipt of the eICR. Without a system of record (EHR of their own), LHJs cannot use existing query/response sharing under the DxF unless they rely on access to longitudinal records, which are only available for a subset of the population via health information exchanges and may not contain the information needed for case investigation. Further implementation will determine whether specific query/response using FHIR APIs may be accessible and scalable for public health, which includes a big dependency on emerging data standards adoption (USCDI+) as well as modernized data systems that can exchange the data. CDPH, together with CDII, will work to identify limitations and challenges (if any) of public health agency data sharing via TEFCA with clinical reporting entities.

Based on investigation of Syndromic Surveillance needs and DxF’s encounter notification work, the DxF should develop guidance to hospitals—with regard to ADT event message standards that would meet both DxF and CDC syndromic surveillance reporting standards. Further, the DxF should explore the role, if any, that the QHIO program might play in supporting hospital ED participation in Syndromic Surveillance.

Over the next three years, CDII will work across CDC, ASTP/ONC, CDPH and LHJs to identify other use case intersections with the DxF in support of public health.

Actionable Steps

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
Play a supportive role in eICR implementation via TEFCA	<ul style="list-style-type: none"> • Support a phased rollout eICR under TEFCA with health systems that span numerous LHJs starting with one hospital and one condition. • Work with CDC/ASTP to determine if additional DxF P&Ps are needed to support the eCR process in California. 	<ul style="list-style-type: none"> • Full rollout of eICR to include all reportable conditions and discontinue manual processes. • Identify additional data needs for full case reporting, especially with longitudinal follow-up. 	Based on 25/26 learnings, implement direct DxF and/or TEFCA participation by PHAs in California.
Investigate opportunities for DxF to support Syndromic Surveillance	<ul style="list-style-type: none"> • Determine workplan (if any) for DxF support for Syndromic Surveillance. This likely would include guidance on event notification data 		

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
	<p>exchange elements and potentially DxP P&Ps.</p> <ul style="list-style-type: none"> • Determine potential role, if any, of the QHIO program to support syndromic surveillance in CA. 		
<p>Work across CDC, ASTP/ONC, CDPH and LHJs to identify other use case intersections with the DxP</p>	<p>Identify guidance and/or policies required to support adoption of interoperability standards in alignment with public health system modernization. Areas of investigation will include:</p> <ul style="list-style-type: none"> ○ API access to immunization records, use of bulk FHIR for population reporting, ○ adoption of USCDI+ in support of public health reporting, and ○ electronic access to vital record information. 	<p>Identify guidance and/or policies required to support adoption of interoperability standards in alignment with public health system modernization. Areas of investigation will include:</p> <ul style="list-style-type: none"> ○ API access to immunization records, use of bulk FHIR for population reporting, ○ adoption of USCDI+ in support of public health reporting, and ○ electronic access to vital record information. 	<p>Identify guidance and/or policies required to support adoption of interoperability standards in alignment with public health system modernization. Areas of investigation will include:</p> <ul style="list-style-type: none"> ○ API access to immunization records, use of bulk FHIR for population reporting, ○ adoption of USCDI+ in support of public health reporting, and ○ electronic access to vital record information.

Pillar #5: Impact Measurement

Introduction

Background

The DxF establishes a clear vision for the exchange of Health and Social Services Information:

Every Californian, and the health and human service providers and organizations that care for them, will have timely and secure access to usable electronic information that is needed to address their health and social needs and enable the effective and equitable delivery of services to improve their lives and wellbeing.

As CDII works toward this vision, measurement of progress will be necessary to determine if goals are being met, to identify areas in need of more attention, and to explore new opportunities to further the aims of health and social services data exchange. These measures of progress and impact will serve to guide CDII's efforts and communicate DxF benefits.

Goal

The goal of the DxF Roadmap Impact Measurement Pillar is to measure the DxF's impact on data exchange, health and social services delivery, and health outcomes, and leverage these measures to inform future DxF design considerations.

Building on the measurement program launched in 2024, this strategy will:

- Track DxF adoption, identifying opportunities to improve DxF participation,
- Identify the volume and types of data exchange between various DxF Participants,
- Describe DxF Participant satisfaction with the quality, timeliness and security of data exchange,
- Assess the impact of data exchange on the delivery of health and social services, and
- Assess the impact of data exchange on well-being and health outcomes.

Central Tenets

The following tenets will guide the development of this Pillar's recommendations.

1. Metrics must be tied to well-defined DxF goals to assess DxF progress and direction.
2. Qualitative and quantitative metrics should assess the effectiveness of DxF-related structures, processes, and outcomes.
3. Metrics should have well-defined definitions, numerators, and denominators, where applicable.
4. Impact Measurement will not focus on real-time DxF monitoring or daily performance, nor will it be a formal evaluation of the program's success and outcomes.
5. Where possible, Impact Measurement will aim to leverage existing data and reporting capabilities to maximize efficiency and reduce burden of data collection.

Landscape

Summary of Current State

In early 2024, CDII began identifying metrics as part of the first phase of DxF Impact Measurement. These metrics are being derived from readily available data and focus primarily on DxF structures and early progress. They include details on DxF Participants and how they participate in the DxF. They also include stakeholder perceptions of data exchange as well as metrics from the Grants program, an important facilitator of data exchange. These data were shared at a September 2024 DxF Implementation Advisory Committee (IAC) meeting. Later in 2024, these metrics will be expanded to include transaction volumes reported by QHIOs.

Problem Definition, Issue Identification and Critical Challenges

While there has been progress in assessing participation in the DxF and early impacts on exchange, there is a need to expand the focus to assess DxF impact on the delivery of health and social services, well-being, and health outcomes.

1. **Framework, Not a Network or Technology.** The DxF's designation as a framework and not a network or prescribed technology creates challenges for measurement. While some DxF elements are common (e.g., the DSA Signing Portal and DxF Participant Directory), there are few required elements, and the use of QHIOs is optional. Without a shared, required infrastructure to monitor or measure, Impact Measurement may need to look outside the DxF and possibly leverage data collected by other organizations or CalHHS Departments. Thus, some measures may capture the broad impact of data exchange and not focus exclusively on the data exchange tied to the DxF.
2. **Multiple Factors Influence Outcomes.** Improvements in well-being and health outcomes are influenced by many factors including genetic, care, social, environmental, economic, and other factors. While increases in data exchange may be associated with improvements in well-being, DxF Impact Measurement cannot detect causal relationships.

Opportunities for Resolution

CDII will develop a phased approach for Impact Measurement, focusing first on the measures reflecting DxF adoption.

1. Phase 1—Continued development of measures of DxF structures and processes (e.g., signatories, QHIO transaction volumes, and grant funding) and DxF Participant satisfaction with quality and timeliness of data.
2. Phase 2—Measures demonstrating improvements in health and social services delivery (e.g., effective transitions in care, reduced readmission rates, reductions in redundant testing, shorter time to referrals, etc.)
3. Phase 3—Measures demonstrating improvements in health and social services outcomes (e.g., reductions in disease incidence)

This phased approach will also incorporate metrics from other DxF Roadmap Pillars including Event Notification, Social Services Data Strategy, Consent and Identity Management, Public Health, and DxF Participant Engagement.

Specific opportunities for Impact Measurement include:

1. Conducting a survey of DxF Participants for targeted input on levels of DxF exchange and impact on health and social services delivery and outcomes.
2. Collaborating with the CDII Insights Lab to leverage its expertise and/or infrastructure to support DxF Impact Measurement.
3. Continuing the collaboration with the Office of the Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology (ASTP/ONC), CalHHS, and others to leverage existing data collection and analysis efforts:
 - a. Participant experience (e.g., American Board of Family Medicine)
 - b. Health care delivery (e.g., claims data analytics from DHCS and HCAI)
 - c. CalAIM initiatives
4. Collaborating with popular technology solution providers (e.g., Epic and PointClickCare) to identify opportunities to assess DxF transaction volumes and impact.

Recommendations

Regulations, Policies and Guidance:

1. **Align QHIO Program requirements and the Impact Measurement Roadmap.** QHIOs are key sources of DxF impact data, including data on the number of individuals and the volume of data being exchanged. QHIO Program requirements—including requirements related to monitoring and reporting—will be updated over time, to ensure consistency with the metrics prioritized for the DxF Impact Measurement approach.

Technical Infrastructure, Architecture and Standards:

1. **Identify hardware, software and technical resources required to collect, manage and report Impact Measurement data and measures.** CDII will require technical resources to collect, manage, and analyze DxF impact data which may include signatory data, participation methods, grants data, transaction volumes, claims data, and DxF Participant perceptions. CDII will explore opportunities to build the necessary technical infrastructure, working with other CalHHS Departments to leverage existing assets where possible and invest in new solutions, as needed.

Financing, Contracting and Operations:

1. **In 2025, expand Phase 1 metrics from their current focus on DxF signatory characteristics and DxF grant outcomes, to include information on QHIO transaction volumes**—a key indicator of the breadth of data exchange occurring in California. Incorporating these new data, CDII will share its Phase 1 metrics with several key constituent groups:

- a. DxF advisory committees including the IAC will receive regularly quarterly updates on DxF impact. These data will help guide the advisory committees’ discussions and guidance regarding the future of the DxF.
 - b. California legislators and staff will receive an annual report summarizing DxF progress and the impact of data exchange on health and social services delivery.
 - c. Current DSA signatories and potential future signatories will receive periodic updates on the DxF and the impact on health and social services delivery. These updates will not only serve to acknowledge the contributions of current DxF Participants, but these data may also help future signatories see the value of the program.
 - d. Californians will be able to access summaries of DxF data exchange as a reflection of the state’s commitment to improving health and social services delivery and realizing its vision of whole person care.
 - e. CDII will continue to publish these periodic reports as new data becomes available, incorporating additional metrics in Phases 2 and 3 as described below.
2. **In 2025, begin to assess the impact of the DxF on the delivery of health and social services** based on prioritized domains and metrics. This Phase 2 of Impact Measurement will go beyond a focus on programmatic and process metrics to begin to assess the impact of the DxF on the delivery of health and social services in California. An initial set of priority domains and sample measures has been identified (*Table 3*). CDII will review the domains and metrics with stakeholders to finalize the Phase 2 approach for implementation.

Table 3. Potential domains and measures for phase 2 of Impact Measurement

Domains	Metrics/Information
Transitions of Care	<ul style="list-style-type: none"> % of discharges resulting in re-admission Time from discharge/referral to receipt of services
Utilization	<ul style="list-style-type: none"> Rate of unnecessary diagnostic testing Total cost of care
Timely Care Delivery	Total length of stay for specific inpatient episodes
Participant Satisfaction	DxF Participant satisfaction with the quality, completeness, or timely receipt of data on the clients they serve
Health Equity	Availability of REaLD and SOGI data in data being exchanged (as reported by QHIOs)
Spotlights	Stories to spotlight the experiences of Participants in implementing the DxF.

3. **In 2026, CDII will extend the assessment to Phase 3—a focus on the DxF impact on well-being and health outcomes.** As part of this phase, CDII may identify and work with an independent, academic researcher to assist with identifying metrics, adding data sources and providing an objective view of DxF impact.
4. **[Ongoing] CDII will engage federal partners, national networks, and TECCA’s Qualified Health Information Networks (QHINs) to identify opportunities to collaborate** on impact measurement. The DxF builds upon data exchange initiatives occurring at the national level. Entities involved in

these initiatives facilitate significant volumes of data exchange and collect information related to such exchange. CDII will engage these partners to determine opportunities to share impact data for mutual benefit. For example, CDII may request data from national networks on transactions they facilitate originating from or directed to entities in California to inform a more complete understanding of data exchange occurring within the state. CDII will look to collaborate with federal partners, including the Assistant Secretary for Technology Policy and Office of the National Coordinator for Health Information Technology (ASTP/ONC) to maintain alignment on measurement strategies, where appropriate.

5. **[Ongoing] CDII will use its Impact Measurement findings to inform design and ongoing management of the DxF.** CDII will regularly review Impact Measurement findings to identify both domains that are performing well and domains needing additional support. CDII will use findings to inform DxF priorities, including to identify technical assistance needs as well as to prioritize development of tools and other resources to support DxF Participants in data exchange. Findings will provide an assessment of the “on the ground” impact of the DxF and inform CDII’s strategic direction for the DxF through future phases of implementation.
6. **[Ongoing] Impact Measurement will collaborate with other Roadmap Pillars** to help support their efforts and provide data to reflect their work and achievements.

Table 4. Summary of Impact Measurement phases

Phase (Dates)	Focus	Metrics
Phase 1 (2024–2025)	Structure and Process	<ul style="list-style-type: none"> • Participation: Details on DxF Participants, organization types, locations, etc. • Exchange: Volume of transactions by transaction type • Satisfaction: Satisfaction on quality and effectiveness of data exchange, as reported by key stakeholders. • Program Support: Metrics from the DxF Grants and QHIO programs reflecting the support offered to assist DxF Participants.
Phase 2 (2025–2026)	Process and Intermediate Outcomes	<ul style="list-style-type: none"> • Effectiveness and Efficiency: Impacts to care delivery including care transitions, utilization, timeliness, use of resources, and equity. • User Experience and Satisfaction: Impacts to user experience exchanging data and providing services for additional key stakeholders.
Phase 3 (2026–2027)	Outcomes	<ul style="list-style-type: none"> • Quality: Impacts to health and social service outcomes and wellbeing.

Actionable Steps

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
Align QHIO Program requirements with Impact Measurement	Review prioritized impact metrics and align with QHIO Program requirements, as needed (ongoing).	Review prioritized impact metrics and align with QHIO Program requirements, as needed (ongoing).	Review prioritized impact metrics and align with QHIO Program requirements, as needed (ongoing).

<i>Technical Infrastructure, Architecture, and Standards</i>	CY 2025	CY 2026	CY 2027
Identify hardware, software and technical resources required to collect, manage and report Impact Measurement data and measures.	<ul style="list-style-type: none"> • Work with Insights Lab and other CalHHS Departments to identify data sources to support DxF impact measurement. • Establish the technical infrastructure to store, manage, and analyze impact measurement data. 	Maintain and upgrade technical infrastructure to store, manage, and analyze impact measurement data as necessary.	Maintain and upgrade technical infrastructure to store, manage, and analyze impact measurement data as necessary.

<i>Financing, Contracting, Operations</i>	CY 2025	CY 2026	CY 2027
[Phase 1] Finalize a Phase 1 data report and share findings.	<ul style="list-style-type: none"> • Collect and analyze data from QHIOs on transaction volumes • Share quarterly updates with DxF advisory groups. • Share DxF data with legislators through an annual report. • Share DxF updates with DxF Participants and the public. 	<ul style="list-style-type: none"> • Collect and analyze data from QHIOs on transaction volumes • Share quarterly updates with DxF advisory groups. • Share DxF data with legislators through an annual report. • Share DxF updates with DxF Participants and the public. 	<ul style="list-style-type: none"> • Collect and analyze data from QHIOs on transaction volumes • Share quarterly updates with DxF advisory groups. • Share DxF data with legislators through an annual report. • Share DxF updates with DxF Participants and the public.

<i>Financing, Contracting, Operations</i>	CY 2025	CY 2026	CY 2027
[Phase 2] Assess the impact of the DxF on the delivery of health and social services based on prioritized domains and metrics.	<ul style="list-style-type: none"> • Discuss Phase 2 domains and metrics with the IAC. • Work with stakeholders to identify and produce Phase 2 metrics. 	<ul style="list-style-type: none"> • Implement the confirmed Phase 2 approach for impact measurement. • Update DxF reporting to include Phase 2 metrics. 	<ul style="list-style-type: none"> • Implement the confirmed Phase 2 approach for impact measurement. • Update DxF reporting to include Phase 2 metrics.
[Phase 3] Assess the impact of the DxF on health outcomes; partner with an independent researcher to further study DxF impact.		<ul style="list-style-type: none"> • Discuss Phase 3 domains and metrics with the IAC. • Work with stakeholders to identify and produce Phase 3 metrics. • Release an RFI/RFP to identify an independent researcher. 	<ul style="list-style-type: none"> • Implement the Phase 3 approach. • Assess the impact of the DxF on well-being and health outcomes and identify needs for 2028 and beyond, in partnership with the independent researcher vendor.
CDII will engage federal partners, national networks, and TEFCA's QHINs to assess opportunities to collaborate on impact measurement.	<ul style="list-style-type: none"> • Outreach to ASTP/ONC, national networks, and QHINs to discuss opportunities to share impact data across data exchange initiatives. 	Execute upon outcomes of discussions, as applicable.	Execute upon outcomes of discussions, as applicable.
Use impact measurement findings to inform design and ongoing management of the DxF.	<ul style="list-style-type: none"> • Assess Phase 1 and early Phase 2 metrics to inform DxF priorities and identify opportunities support data exchange. 	Assess Phase 1 and 2 metrics to inform DxF priorities and identify opportunities to further support data exchange.	Assess Phase 1 and 2 metrics to inform DxF priorities and identify opportunities to further support data exchange.
Additional Measurement to Support Roadmap Pillars	As the DxF Roadmap Pillars execute on their plans, partner with each team to identify metrics to support their assessment.	As the DxF Roadmap Pillars execute on their plans, partner with each team to identify metrics to support their assessment.	As the DxF Roadmap Pillars execute on their plans, partner with each team to identify metrics to support their assessment.

Pillar #6: Participant Engagement

Introduction

Background of Issues

The DxF requires organizations specified in AB133 to become DxF Participants by signing the DxF's DSA and completing an entry in the DxF Participant Directory that explains how they intend to exchange information. Most of these mandatory Participants were required to begin sharing information in accordance with the DSA and its P&Ps by January 31, 2024. Other organizations that wish to participate in the DxF may also follow the same process. Once an organization signs, they need to determine their requirements for exchange.

There are a number of challenges related to supporting and monitoring compliance with DxF requirements among prospective and current Participants. First, many mandatory signatories have not yet signed the DSA. Second, some mandatory signatory categories—including “Physician organizations and medical groups,” are not clearly defined in statute, making it difficult to measure the total number of required DSA Signatories. Finally, the completion rate of DxF Participant Directory entries among signatories is significantly below 100%, and there are major inconsistencies with how signatories fill out the DxF Participant Directory.

Goal

The goal of the DxF Roadmap Participant Engagement Pillar is to strengthen pathways and processes to engage with mandatory and voluntary DSA signatories to increase participation in and compliance with the DxF and enhance DxF Participant monitoring.

Central Tenets

The following tenets will guide the development of this priority area's recommendations.

1. State policy and guidance should clearly indicate what types of organizations are mandatory signatories and what types of organizations can become Voluntary Signatories.
2. All DxF Participants should have access to information and assistance to help them adopt the DxF regardless of their data exchange maturity level.
3. Levers at the disposal of various state agencies should be used to encourage widespread adoption of the DxF and reinforce signatory compliance.
4. Efforts to support DxF Participants should align with the priorities of existing state and federal programs such as CalAIM and TECCA.
5. An effective engagement plan should leverage, to the extent feasible, mechanisms and resources that are cost-free or would incur the lowest cost to the state, stakeholders, and DxF Participants.

Landscape

Summary of Current State

As of September 2024, the DxF has over 2,500 signed DSAs representing over 4,000 DxF Participants. To date, over 80% of all required hospitals and health plans have signed. After discounting voluntary signatories, this indicates that about 50% of all mandatory signatories have signed the DSA.

Also as of September 2024, only 33% of all mandatory DSA signatories who have signed (1,238 out of 3,793) have completed a corresponding entry in the DxF Participant Directory. Of those entries, many contain inaccuracies that misrepresent the types of data exchange activities they undertake and exchange methods they intend to use, hindering monitoring efforts. For example, CDII has observed that some DxF Participants state that they engage in certain data exchange activity types such as generation of admission and discharge events, even when they do not.

Table 5. DxF Signing Portal Records and DxF Participant Directory Entries as of September 10, 2024

DxF Participant Category based upon Type Analysis	Unique DxF IDs (records)
Hospitals (General acute care settings and acute psychiatric settings)	323 of 463 (70%)
Physician organizations and medical groups	1,797 (of undefined)
Skilled Nursing Facilities (SNFs)	824 of 1,190* (69%)
Health Care Service Plans and Disability Insurers (Plans)	88 of 104 (85%)
Clinical Laboratories	319 of 2,480 (13%)
Qualified HIOs (QHIOs)	9 of 9 (13 due to aliases)
County —health, public health, social services	49
County (DSA has Primary Org, county level only)	15
State	5
Other (CBOs, non-QHIO Intermediaries, others)	416
Primary Organization with Subs, has indicated will exchange at this level	33
Primary Organization with Subs, no Primary level exchange indicated	191
Total Participant Type Count	4,073

Problem Definition, Issue Identification and Critical Challenges

A number of issues are contributing to the challenges with engaging, supporting and monitoring DxF Participants and their compliance with DxF requirements.

1. **Definitions of some required signatory groups** were not provided in statute and need further clarification to support education, technical assistance, compliance, and enforcement.
2. **Lack of DxF enforcement mechanisms** results in some organizations not feeling compelled to comply.
3. **Lack of understanding around DxF requirements, benefits, and risks** results in some organizations not seeing a clear benefit to participating in the DxF. The value of data exchange may not be clear or is slow to realize. And some entities are concerned that exchanging HSSI with non-HIPAA covered entities could increase their liability.
4. **DxF Participant Directory limitations**, including usability and lack of capabilities that support DxF Participant collaboration and workshopping, diminish its value. It also lacks automation for back-end data collection and reporting, resulting in resource-intensive manual input processes.
5. **Some DxF Participants have limited technical infrastructure and resources**, making it difficult to participate in and comply with the DxF.

Opportunities for Resolution

To address the issues identified above, CDII will develop a Participant Engagement plan designed to increase mandatory and voluntary participation, improve the functionality, reliability and completeness of the DxF Participant Directory, improve Participant monitoring mechanisms, and support stakeholder technical and programmatic compliance and understanding of the DxF and its value. The plan will also include measures of success to:

1. Assess if more mandatory DxF Participants are signing the DSA;
2. Identify which mandatory entities are not participating and why; and
3. Assess completion and accuracy of Participant Directory entries.

The following table outlines identified issues and opportunities to support a successful Participant Engagement plan.

Table 6. Summary of issues and opportunities to resolve them

Issue	Opportunities
Ambiguous Definitions of Required signatory Groups	<ul style="list-style-type: none"> • Pursue state legislative changes that allow for the establishment of a governing board and provides CDII the authority to develop and implement definitions for Provider Organizations and Medical Groups (POMGs) and potentially expand the scope of required signatory groups to be more inclusive
Lack of DxF Enforcement Mechanisms	<ul style="list-style-type: none"> • Pursue state legislative changes that empower CDII and other state departments to create new enforcement mechanisms • Strengthen cross-department coordination to exercise regulatory and contracting authorities to advance DxF compliance and objectives • Regularly communicate DxF signatory compliance and participation rates to position the DxF brand as a benefit and highlight successes

Issue	Opportunities
Lack of Understanding around DxF Requirements and Benefits	<ul style="list-style-type: none"> • Execute communications, technical assistance, learning collaboratives, and stakeholder engagement plan that includes tailored strategies by signatory group that supports DxF adoption • Develop and publish a DxF “Welcome Guide” to educate and serve as a directory for prospective and current Participants
DxF Participant Directory Limitations	<ul style="list-style-type: none"> • Update DxF Participant Directory infrastructure
Stakeholder Technical Infrastructure and Resourcing Limitations	<ul style="list-style-type: none"> • Potential funding and grant program to promote equitable health information exchange and updates to technical infrastructure

Recommendations

Regulations, Policies and Guidance

1. **Establish and Expand Definitions of Mandatory Signatories by:**
 - a. Pursuing and leveraging state legislative changes would allow for the establishment of a governing board and provide CDII the authority to develop and implement definitions for POMGs.
 - b. Expanding required signatory groups beyond current definitions to include organizations that would mutually benefit from participation in the DxF.

2. **Implement a Statewide Communication and Education Plan, Including Tailored Communication Strategies for Signatory Groups** with measurable objectives aimed to describe, position, and drive adoption of the DxF and facilitate DxF Participant engagement and onboarding. Activities may include:
 - a. Communicating DxF educational materials and updates via official and high-exposure channels such as All-Plan Letters.
 - b. Clarifying questions and misconceptions regarding the DxF (e.g., concerns with robustness of data privacy).
 - c. Tailoring communication strategies by stakeholder groups by:
 - i. Identifying non-compliant mandatory signatories by signatory category,
 - ii. Developing an outreach strategy that identifies communication channels and channel partners to reach non-compliant required signatories, and
 - iii. Identifying and securing resources for partners to engage with non-compliant signatories with tools and supports to help non-compliant required signatories engage in the DxF.

3. **Publish a DxF Welcome Guide** to support DxF Participants, including by educating them about the DxF, how participation might add value for them, and how exactly to participate. The guide may also serve as a resource directory and act as a tool to evaluate and understand DxF Participants’ current capacity to comply with DxF technical and programmatic requirements.

4. **Develop an Accountability Framework** with mechanisms for holding mandatory signatories accountable for signing the DSA and complying with DxF participation requirements. Levers may include:
 - a. Pursuing legislative action to refine DxF governance and introduce enforcement authorities.
 - b. Developing processes to leverage peer agency (e.g., state departments/agencies) regulatory enforcement mechanisms, such as integration of DSA signing and DxF Participant Directory completion with provider recertification cycles.
 - c. Establishing a regular cadence for calculating and communicating compliance rates by signatory type, including distributing to legislators and associations to support awareness.
5. **Ensuring continued alignment with state and national frameworks and programs** such as CalAIM and TECCA to minimize additional burden on DxF Participants and facilitate compliance

Technical Infrastructure, Architecture and Standards

1. **Improve DxF Participant Directory Infrastructure and related DxF Participant Directory-processes** to allow for efficient data entry, analysis, and use to monitor signatories and DxF impact (i.e., identifiers and repository of organization exchange requirements).
2. **Support DxF Participant Technical Capacity** specifically targeting under-resourced entities to help them comply with DxF technical requirements:
 - a. Develop and implement a highly standardized, reproduceable, and sustainable strategy for supporting equitable statewide access to necessary technical infrastructure to facilitate DxF Participant onboarding and participation.
 - b. Integrate and collaborate where possible with technologies such as EHRs as an accessible and simplified option to support DxF Participant compliance.

Financing, Contracting and Operations

1. **Identify Potential Funding Sources to Promote Equitable Exchange**, particularly to support the state's most disproportionately under-resourced organizations, DxF Participants, and geographic regions. This may include another DxF grant program designed to provide financial support for technical infrastructure development, maintenance, and improvements.
2. **Identify and Secure Funding for Stakeholder Engagement Activities and Internal Infrastructure** (e.g., DxF Participant Directory 2.0)
3. **Prepare Procurements and Contracts with vendors to support planned activities**, including stakeholder communications/engagement, technical infrastructure development, and data analytics, as needed.

Actionable Steps

<i>Regulation, Policies, and Guidance</i>	CY 2025	CY 2026	CY 2027
Establish trusted denominators	<ul style="list-style-type: none"> • Workshop methods to define required signatory denominators (e.g., via the POMG definition workgroup) • Develop authorities needed to define denominators 	Define and implement updated signatory group definitions (e.g., for POMGs)	Define and implement updated signatory group definitions (e.g., for POMGs)
Statewide communication	Welcome Guide development, implementation, and dissemination	Welcome Guide development, implementation, and dissemination	Welcome Guide development, implementation, and dissemination
	Develop and submit a statewide communications plan	Execute the statewide communications plan	Execute the statewide communications plan
Targeted signatory group communications	Conduct stakeholder engagement based on chosen events	Alter and continue stakeholder engagement based on results and lessons learned	Alter and continue stakeholder engagement based on results and lessons learned
Measure success of Participant Engagement Plan	Measure success of engagement activities in year one and integrating with DxF Long-Term Impact Measurement strategy where possible.	Continue measuring and refining success metrics as necessary.	Continue measuring and refining success metrics as necessary.
Accountability Framework	<ul style="list-style-type: none"> • Regularly calculate and communicate signatory compliance rates and data exchange activity. • Identify opportunities to leverage state department/agency authoritative mechanisms and aligned priorities to enforce DSA compliance 	<ul style="list-style-type: none"> • Regularly calculate and communicate signatory compliance rates and data exchange activity. • Identify opportunities to leverage state department/agency authoritative mechanisms and aligned priorities to enforce DSA compliance 	<ul style="list-style-type: none"> • Regularly calculate and communicate signatory compliance rates and data exchange activity. • Identify opportunities to leverage state department/agency authoritative mechanisms and aligned priorities to enforce DSA compliance

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<i>Technical Infrastructure, Architecture, Standards</i>	CY 2025	CY 2026	CY 2027
Infrastructure	Determine and implement upgrades to PD infrastructure	Identify PD infrastructure outcomes	Identify PD infrastructure outcomes

<i>Financing, Contracting, Operations</i>	CY 2025	CY 2026	CY 2027
Administer Equity Grant Program	Develop Equity Grant Program and funding mechanisms, publish RFPs, and collect proposals	Select grantees and begin disbursing funds	Continue to disburse funds and monitor program compliance and performance

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Cross-Pillar Considerations

While the DxF Roadmap presents recommendations across six discrete priority areas, there are a number of considerations that span across multiple Pillars. This section describes implications of the DxF Roadmap on three cross-Pillar topics: QHIOS; Privacy; and Identity and Access Management.

Qualified Health Information Organizations

QHIOs are entities designated by CDII to facilitate the secure exchange of HSSI in the DxF. QHIOs assist entities as they create and respond to information requests, send and receive the results of tests or referrals, and solicit and forward notifications of admissions or discharges.

Many recommendations in the DxF Roadmap implicate QHIOs and the QHIO Program. QHIOs are important enablers of data exchange among DxF Participants. While use of a QHIO is optional – Participants may choose to exchange HSSI via any method that complies with the DSA and its P&Ps – many Participants choose to use QHIOs to support their participation in data exchange. Recent data from the DxF Participant Directory shows that approximately 80% of the ambulatory providers that have entered their choices report using a QHIO to meet DxF requirements.

The widespread use of QHIOs by DxF Participants makes them critical partners in driving improvements in data exchange. Coordinated efforts between CDII and QHIOs can drive a degree of consistency and standardization to enable effective and efficient exchange. While implementation of the Roadmap’s QHIO-relevant recommendations will most directly affect those Participants working with a QHIO, these actions can also drive a “critical mass” of change that will impact those exchanging data through other means and the landscape of data exchange in California as a whole.

QHIOs are referenced in many of the Roadmap Pillar recommendations, including those pertaining to establishing a coordinated approach to Event-Based Exchange under the DxF, developing a consent management architecture, and demonstrating impact of the DxF. Specific connections between the QHIOs and DxF Roadmap Pillars are described in the table below.

Table 7. Connections between QHIOS and DxF Roadmap Pillars

Pillar	Connections to QHIO Program
Event Notification	<ul style="list-style-type: none"> • QHIOs will provide critical inputs to the architecture for Event-Based Exchange. • QHIOs may also play significant roles as actors in the architecture for Event-Based Exchange, potentially using centralized services, participating in person matching, consolidating and exchanging events, and generating and routing notifications. • QHIOs are collaborating to develop a standard format and mechanism for exchanging rosters with other QHIOs.
Social Services Data Strategy	<ul style="list-style-type: none"> • QHIOs could potentially support local social service data exchange activities.
Consent and Identity Management	<ul style="list-style-type: none"> • QHIOs will be critical inputs to and implementers of an efficient and scalable consent management architecture.

	<ul style="list-style-type: none"> • QHIOs may be required to use a consent management service, if such a service is established. • QHIOs may play a role as an early adopter of an expanded ASCMI eConsent service.
Public Health Data	<ul style="list-style-type: none"> • The DxF will need to stay aligned with the evolving federal data exchange landscape and determine QHIO (DxF) versus QHIN (TEFCA) roles in effectively supporting public health functions identified in the Public Health Pillar. • QHIOs may play a role in supporting hospital ED participation in syndromic surveillance.
Impact Measurement	<ul style="list-style-type: none"> • QHIOs are key sources of DxF impact data, including data on the number of individuals and the volume of data being exchanged. • QHIO Program requirements – including requirements related to monitoring and reporting – will be updated over time, to ensure consistency with the metrics prioritized for the DxF Impact Measurement approach.
Participant Engagement	<ul style="list-style-type: none"> • QHIOs enable data exchange for many DxF Participants, including the majority of ambulatory providers (based on the current sample of DxF Participants entering their choices in the DxF Participant Directory). • Engagement activities may include efforts to highlight for DxF Participants (and prospective participants) the role of QHIOs in supporting data exchange under the DxF. • QHIOs will actively assist CDII in outreach and education to their clients (e.g., to support the entering of choices in the DxF Participant Directory).

Privacy

The legal framework governing data privacy in California is complex, shaped by various federal and state laws that protect individuals' privacy while enabling secure exchange of HSSI.

Federal Laws

HIPAA and its privacy rule set national standards for the protection of an individual's health information held by "covered entities" – generally health care providers and health plans.⁴⁵ Identifiable health information held by covered entities is called "protected health information," or PHI. The Privacy rule requires privacy safeguards, limits the use and disclosure of PHI, and grants individuals the right to access, correct, or direct the sharing of their data. HIPAA permits data-sharing between covered entities – such as Medi-Cal Managed Care Plans, behavioral health plans, providers, and health systems for purposes of treatment, payment, and health care operations without an individual's authorization.⁴⁶ HIPAA also permits data-sharing with non-covered entities – such as housing providers – for purposes of treatment.⁴⁷

Other federal laws provide targeted protections for specific types of HSSI. Title 42 C.F.R. Part 2⁴⁸ governs the confidentiality of SUD data held by certain SUD providers or programs. To be subject to 42 C.F.R. Part 2, a provider or program must receive federal assistance; and hold itself out as and provide SUD treatment, diagnosis, or referral services. When it applies, 42 C.F.R. Part 2 is more restrictive than HIPAA in that it requires individual authorization for disclosures of SUD data even for purposes of treatment, payment and care coordination. Recent updates to the 42 C.F.R. Part 2 regulations have aligned the rule more closely with HIPAA, allowing individuals to provide broad consent for disclosures of their SUD data for treatment, payment and healthcare operations using a single form, to designate categories of recipients rather than designating individual recipients; and provide a consent expiration date of "none."

Other federal law governing certain types of health records are the Family Educational Rights and Privacy Act⁴⁹ (FERPA), which regulates access to student health and education records, and the Individuals with Disabilities Education Act (IDEA)⁵⁰ which contain additional confidentiality provisions for records of students with disabilities.

⁴⁵ U.S. Department of Health and Human Services. "The HIPAA Privacy Rule." September 27, 2024. <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>.

⁴⁶ U.S. Department of Health and Human Services. "The HIPAA Privacy Rule." September 27, 2024. <https://www.hhs.gov/hipaa/for-professionals/privacy/index.html>.

⁴⁷ *Code of Federal Regulations*, Title 45, § 164.502 (2023); U.S. Department of Health and Human Services. "FAQ 3008 Does HIPAA permit health care providers to share protected health information (PHI) about an individual with mental illness with a third party that is not a health care provider for continuity of care purposes?" June, 8, 2020. <https://www.hhs.gov/guidance/document/faq-3008-does-hipaa-permit-health-care-providers-share-protected-health-information-phi>.

⁴⁸ Code of Federal Regulations, Title 42, Part 2 (2010).

⁴⁹ Family Educational Rights and Privacy Act (FERPA). 20 U.S.C. § 1232g. (1974).

⁵⁰ Individuals with Disabilities Education Act, 20 U.S.C. § 1400 (2004).

State Laws

In addition to these federal laws, HSSI in California is also protected by state health privacy laws and regulations, which have their own confidentiality and consent requirements.

The Confidentiality of Medical Information Act (CMIA)⁵¹ for the most part mirrors HIPAA, though it applies, through its definition of “provider of healthcare,” more broadly than HIPAA, and is more restrictive in certain respects, such as the requirements for disclosure authorization forms.⁵² The CMIA also provides for both civil and criminal penalties for violations, while HIPAA only allows for civil penalties; the CMIA also sets higher maximum penalties than HIPAA for certain types of violations.⁵³

The Lanterman-Petris-Short (LPS) Act⁵⁴ specifically protects the confidentiality of inpatient mental health data and allows the disclosure of such information, absent consent, only in limited circumstances that are more narrow than HIPAA.⁵⁵

California has laws that protect the confidentiality of SUD information as well, which similarly allow disclosure of SUD records without authorization only in limited circumstances more narrow than HIPAA.⁵⁶ The California Welfare and Institutions Code creates additional protections.^{57,58}

Importantly, to promote data sharing and care coordination, the California State legislature passed AB133 in 2021 to ease state privacy restrictions in alignment with the goals of CalAIM. This law permits the sharing of data among Medi-Cal partners for purposes of implementing CalAIM and preempts more restrictive state laws when it comes to obtaining an individual’s consent. This means that, generally, federal law and its consent requirements govern the exchange by Medi-Cal partners of health and HSSI information in California when exchanging for the purposes of implementing CalAIM.⁵⁹

Given the complexity of state and federal laws and regulations, health care and social service organizations often struggle to navigate privacy requirements. The DxF Roadmap includes recommendations to develop standards, use cases and other educational materials to help stakeholders navigate privacy laws related to Event Notifications, Social Services Data Strategy, Consent and Identity Management, and Public Health.

⁵¹ California Civil Code. § 56–56.37. California Confidentiality of Medical Information Act.

⁵² California Civil Code § 56.11.

⁵³ California Civil Code § 56.36.

⁵⁴ California Welfare and Institutions Code. §§ 5328-5330. Lanterman-Petris-Short Act.

⁵⁵ California Welfare and Institutions Code § 5328.

⁵⁶ California Health and Safety Code § 11845.5.

⁵⁷ California Welfare and Institutions Code. § 827.

⁵⁸ California Welfare and Institutions Code. § 10850.

⁵⁹ California State Legislative. Assembly Bill 133, Chapter 143. 2021.

Identity and Access Management

ASTP/ONC defines identity management as the process of establishing and verifying the identities of providers, patients, and other stakeholders to ensure appropriate access to all health-related information, meet regulatory requirements, link health information with the correct, individual, and effective care coordination across organizations.⁶⁰ A comprehensive healthcare identity management framework integrates several key elements to ensure secure, efficient, and compliant handling of individual identities. These elements include identity assurance, access management, and identity linkage.

The DxF Roadmap includes three components of identity and access management:

- 1) **Identity assurance** is a process used to assure that identifying information about an individual is associated with the correct person. It usually includes processes in which an individual provides documented evidence identifying themselves to an authority. This process may result in granting the individual credentials later used in access management.
- 2) **Access management** sometimes also called identity and access management (IdAM), is the process by which an individual authenticates themselves, often using credentials issued upon completion of identity assurance, and is granted access to data based on their identity and business rules for their role in managing the data. These processes help manage access to electronic health information. The processes may enable different access for individuals that are the subject of the information, their representative(s), their family member(s), or their provider(s). Access management often involves Identity Governance and Administration (IGA) to streamline access assignments and maintain regulatory compliance.
- 3) **Person matching** and **record linking** are related processes, sometimes used interchangeably. Person matching links person attributes such as name, date of birth, address, phone number, or unique identifiers that establish a digital identity across systems when the identities are associated with the same real person. Record linking links records, such as items of health or social services information, belonging to the same real person into a single, consolidated record. Person matching may use a master person index (MPI) technology that employs sophisticated probabilistic and/or referential methods, and sometimes machine learning, to match identities. Health care entities often use MPIs in turn to assist in record linking to by matching identities associated with different elements of health and social services information.

Developing and implementing a robust IdAM strategy is a theme within the Consent and Identity Management Pillar recommendations. Recommendations include creating guidance, P&Ps, and technical standards for identity management, as well as exploring centralized or coordinated federated services to support identity management capabilities. The implementation of these recommendations will include input from the Office of Technology and Solutions Integration (OTSI), the California Department of Technology (CDT), and other agencies.

⁶⁰ U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology. *Identity Management Guide*. Version 1.1. December 6, 2017. <https://www.healthit.gov/sites/default/files/identitymanagementguidev5.13.pdf>.

Many of the Pillars in the DxF Roadmap rely on reliable person matching and/or record linking. Some, especially those that require or allow an individual to access or change their own information, may also rely on identity assurance and access management. Specific connections between Identity and Access Management and DxF Roadmap Pillars are described in the table below.

Table 8. Connections between Identity Management and DxF Roadmap Pillars

Pillar	Connections to Identity Management
Event Notifications	<ul style="list-style-type: none"> • Person matching capabilities are necessary to support organizations in matching individual identities from a roster to the identities of individuals that are the subject of an event. • Statewide identity management services can support person matching for rosters, events, and notifications.
Social Services Data Strategy	<ul style="list-style-type: none"> • Person matching capabilities are necessary to match individuals with their HSSI across various health and social services organizations. • Access management capabilities may be needed and can support appropriate access to HSSI for non-HIPAA covered entities.
Consent and Identity Management	<ul style="list-style-type: none"> • Person matching capabilities are needed to accurately link individuals with their consents to share information. • Identity verification and access management must be embedded in a centralized or federated consent management platform to ensure that the appropriate individuals have access to consent data.
Public Health	<ul style="list-style-type: none"> • Person matching capabilities are necessary to ensure appropriate management and follow-up of reportable conditions identified through eCR to public health agencies.
Impact Measurement	<ul style="list-style-type: none"> • Person matching capabilities are needed to link individually identifiable data sets from multiple sources to construct measures, particularly for outcome measures.

Behavioral Health

California, like most states, faces a significant set of challenges in addressing the behavioral health needs of its residents. Nearly one in seven California adults experiences a mental illness,⁶¹ while approximately one in 10 Californians over age 12 struggled with a SUD in the past year.⁶² Despite the prevalence of behavioral health needs, evidence suggests that individuals are not consistently getting the care they need, with nearly two-thirds of adults with a mental illness not receiving treatment⁶³ and similar rates of missed care among commercial plan members with new episodes of alcohol or other drug dependence.⁶⁴ The burden of behavioral health needs is also unevenly distributed, with disproportionate impacts to vulnerable populations based on race, income, and incarceration status.^{65,66}

CalHHS and the Administration more broadly have made a series of investments to support those living with mental health and substance use disorders.⁶⁷ A major component of CalHHS' behavioral health strategy is implementation of Proposition 1, a voter initiative passed in March 2024 to fund modernizing investments to the state's behavioral health care system. Behavioral health transformation spurred by Proposition 1 complements California's existing major behavioral health initiatives including CalAIM, the California Behavioral Health Community-Based Organized Networks of Equitable Care and Treatment (BH-CONNECT) Demonstration proposal, the Children and Youth Behavioral Health Initiative (CYBHI), Medi-Cal Mobile Crisis and 988 expansion, and the Behavioral Health Continuum Infrastructure Program (BHCIP).⁶⁸

The effective management of behavioral health conditions relies on accurate and timely data exchange. However, the behavioral health system faces unique challenges in achieving seamless exchange of health and social services information. Many behavioral health providers were not eligible for HITECH incentives that subsidized the purchase of electronic health records (EHRs). Coupled with high implementation costs and a lack of industry consensus on the essential components of behavioral health-focused

⁶¹ California Health Care Foundation. *Mental Health Almanac 2022*. July 2022. <https://www.chcf.org/wp-content/uploads/2022/07/MentalHealthAlmanac2022.pdf>.

⁶² California Health Care Foundation. *Substance Use Disorder Almanac 2022*. January 2022. <https://www.chcf.org/wp-content/uploads/2022/01/SubstanceUseDisorderAlmanac2022.pdf>.

⁶³ California Health Care Foundation. *Mental Health Almanac 2022*. July 2022. <https://www.chcf.org/wp-content/uploads/2022/07/MentalHealthAlmanac2022.pdf>.

⁶⁴ California Health Care Foundation. *Substance Use Disorder Almanac 2022*. January 2022. <https://www.chcf.org/wp-content/uploads/2022/01/SubstanceUseDisorderAlmanac2022.pdf>.

⁶⁵ Ibid.

⁶⁶ California Health Care Foundation. *Mental Health Almanac 2022*. July 2022. <https://www.chcf.org/wp-content/uploads/2022/07/MentalHealthAlmanac2022.pdf>.

⁶⁷ California Health and Human Services. "Guiding Principles and Strategic Priorities." Accessed October 31, 2024. <https://www.chhs.ca.gov/guiding-principles-strategic-priorities/>.

⁶⁸ California Health and Human Services. "Behavioral Health Reform." Accessed October 31, 2024. <https://www.chhs.ca.gov/behavioral-health-reform/>.

information systems, they have lower rates of EHR adoption than their physical health peers and less experience and capacity to participate in health information exchange initiatives.⁶⁹ Behavioral health care delivery can also involve a more diverse range of actors than traditional health care, each with varying capabilities and resources to support data exchange. Uncertainty and concerns about risk regarding the legal implications for exchanging sensitive SUD information also present obstacles. Together, these factors create a complex landscape that hinders the effective flow of critical behavioral health data, impacting the quality of care delivered.

The DxF Roadmap includes recommendations to improve data exchange within the behavioral health system, including by developing guidance, standards, and shared services. Specific connections between behavioral health and DxF Roadmap Pillars are described in the table below. As CalHHS continues to prioritize and implement efforts to support individuals with behavioral health needs, the DxF Roadmap will be updated to align with existing and emerging initiatives.

Table 9. Connections between Behavioral Health and DxF Roadmap Pillars

Pillar	Connections to Behavioral Health
Event Notification	<ul style="list-style-type: none"> • Behavioral health providers may participate in Event-Based Exchange under the DxF, potentially leveraging centralized or coordinated services that may be established. • Behavioral health events could be considered as a potential use case for Event-Based Exchange (e.g., entry into the county behavioral system acting as a trigger for notification).
Social Services Data Strategy	<ul style="list-style-type: none"> • Behavioral health providers include social service providers and CBOs that will benefit from efforts to strengthen data exchange infrastructure and resourcing.
Consent and Identity Management	<ul style="list-style-type: none"> • Consent management use cases, tool kits, and educational resources will support providers in exchanging data related to substance use.
Impact Measurement	<ul style="list-style-type: none"> • Future stages of DxF Impact Measurement may include metrics to assess the impact of exchange on behavioral health care delivery and/or outcomes and to track progress on CalHHS behavioral health priorities (e.g., Behavioral Health Transformation).
Participant Engagement	<ul style="list-style-type: none"> • Many behavioral health providers, such as provider organizations and acute psychiatric hospitals, are required signatories of the DSA and will receive outreach to support data exchange and compliance with DxF requirements. • Behavioral health providers will be important stakeholders in CalHHS' technical assistance efforts and a key audience for the DxF Welcome Guide.

⁶⁹ Medicaid and CHIP Payment and Access Commission. *Chapter 4: Encouraging Health Information Technology Adoption in Behavioral Health*. June 2022. <https://www.macpac.gov/wp-content/uploads/2022/06/Chapter-4-Encouraging-Health-Information-Technology-Adoption-in-Behavioral-Health.pdf>.

Appendix I. Glossary of Abbreviations

Abbreviation	Definition
ADT	admission, discharge, and transfer
AIMS	Association of Public Health Laboratories' (APHL) Informatics Messaging Services
APD	Advance Planning Document
APHL	Association of Public Health Laboratories
APIs	application programming interfaces
ASCFI	Authorization to Share Confidential Medi-Cal Information
ASTP/ONC	Assistant Secretary for Technology Policy/Office of the National Coordinator for Health Information Technology
BAA	business associate agreement
BHCIP	Behavioral Health Continuum Infrastructure Program
CalAIM	California Advancing and Innovating Medi-Cal
CalHHS	California Health & Human Services Agency
CalREDIE	California Reportable Disease Information Exchange
CBO	community-based organization
CDA	Clinical Document Architecture
CDC	U.S. Centers for Disease Control and Prevention
CDII	Center for Data Insights and Innovation
CDPH	California Department of Public Health
CDSS	California Department of Social Services
CDT	California Department of Technology
CHCF	California Health Care Foundation
CIE	Community Information Exchange
CMIA	Confidentiality of Medical Information Act
CMS	Centers for Medicare & Medicaid Services
CoC	Continuums of Care
CYBHI	Children and Youth Behavioral Health Initiative
DHCS	(California) Department of Health Care Services
DSA	Data Sharing Agreement
DSAG	Data Sharing Authorization Guidance
DxF	Data Exchange Framework
ECM	Enhanced Care Management
eCR	electronic case reporting
ED	emergency department
EHR	electronic health record
ENS	Event Notification Service
FERPA	Family Educational Rights and Privacy Act
FFP	Federal Financial Participation

Abbreviation	Definition
FHIR	Fast Healthcare Interoperability Resource
FoPH	Future of Public Health
HCAI	(California) Department of Health Care Access and Information
HIE	health information exchange
HIO	health information organization
HIPAA	Health Insurance Portability and Accountability Act
HITECH	Health Information Technology for Economic and Clinical Health Act
HL7	Health Level Seven
HMIS	Homeless Management Information System
HSC	Health and Safety Code
HSSI	Health and Social Services Information
HTI	Health Data, Technology, and Interoperability
HUD	U.S. Department of Housing and Urban Development
IAC	Implementation Advisory Committee
IDaM	identity and access management
IDEA	Individuals with Disabilities Education Act
IGA	Identity Governance and Administration
IHE	Integrating the Healthcare Enterprise
LHJ	local health jurisdiction
LPS	Lanterman-Petris-Short Act
Mass Hlway	Massachusetts Health Information Highway
MCP	Managed Care Plan
MPI	master patient index
OTSI	Office of Technology and Solutions Integration
P&P	Policy & Procedure
PATH	Providing Access and Transforming Health
PCDH	Patient Centered Data Home™
PCP	primary care provider
PD	Participant Directory
PHA	public health agency
PHI	protected health information
POMGs	Provider Organizations and Medical Groups
QHIN	Qualified Health Information Network
QHIO	Qualified Health Information Organization
RFIs	requests for information
RFP	request for proposals
SDOH	social determinants of health
SHIG	State Health Information Guidance
SMHS	specialty mental health service

Abbreviation	Definition
SNAP	Supplemental Nutrition Assistance Program
SNF	skilled nursing facility
SOCI	Stewards of Change Institute
SSO	single sign-on
SUD	substance use disorder
TEFCA	Trusted Exchange Framework and Common Agreement
TPO	treatment, payment, and health care operations
USCDI+	United States Core Data for Interoperability Plus
WIC	Women, Infants and Children

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