CALIFORNIA HEALTH & HUMAN SERVICES AGENCY

CENTER FOR DATA INSIGHTS AND INNOVATION

Data Exchange Framework Roadmap

2025–2027

PUBLISHED: February 2025

CalHHS
California Health & Human Services Agency

CENTER FOR
DATA INSIGHTS
AND INNOVATION
CALIFORNIA HEALTH &
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Introduction

Background and Purpose

In 2024, the Center for Data Insights and Innovation (CDII) facilitated a comprehensive planning process to develop a statewide vision for the next phase of Data Exchange Framework (DxF) implementation. This planning, which included significant engagement with a broad range of stakeholders, resulted in the development and publication of the three-year **DxF Roadmap.**

The purpose of the 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 in support of these priorities.

The DxF Roadmap describes how the state and stakeholders can work together to collectively invest in data exchange efforts that advance whole person care, leveraging efforts across the health and human service ecosystems, inside and outside of government. CDII collaborated with the DxF Implementation Advisory Committee (IAC), CalHHS state departments, and other subject matter experts and stakeholders to develop the DxF Roadmap. Feedback received during a public comment period in Fall 2024 also informed the Roadmap's final recommendations.

Through implementation of the DxF Roadmap, CDII will advance CalHHS' vision for data exchange, in alignment with the guiding principles of the DxF and CalHHS.

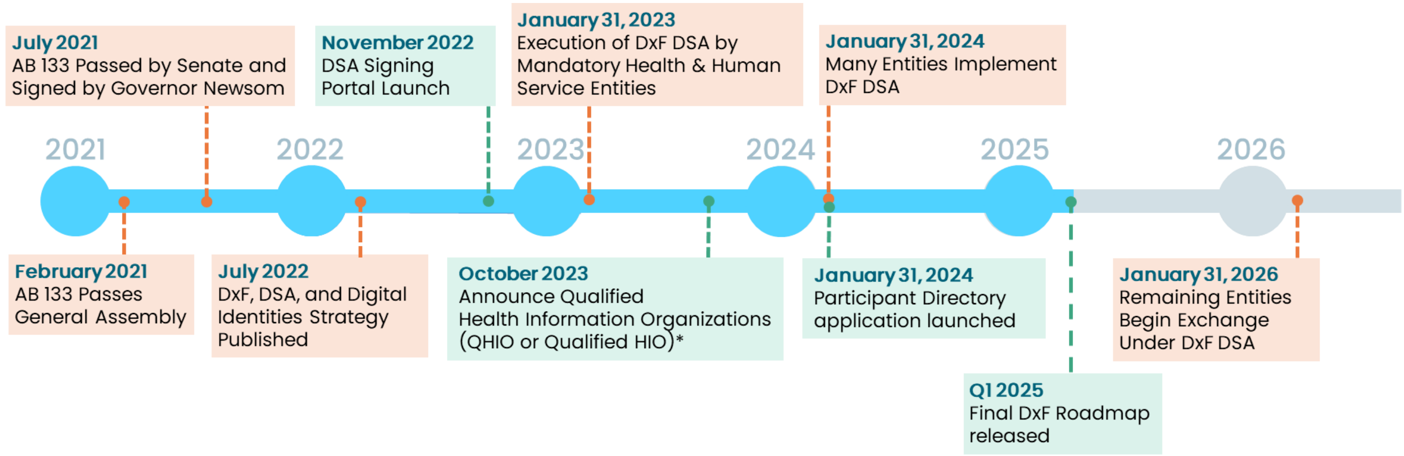
The Data Exchange Framework Vision

"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.""

Advancing health equity is a critical component of this vision and both sets of principles. Successful implementation of the DxF Roadmap entails not only improving the state of data exchange in California but doing so in a way that reduces inequities and disparities, among both the entities participating in exchange as well as the individuals they serve. The imperative to better understand and address health inequities and disparities – across demographics, geography, and other factors - is a cornerstone of the Roadmap's recommendations.

DxF Background

Figure 1. DxF Implementation Timeline



What is the DxF? Established by California Health and Safety Code (HSC) § 130290, the DxF is California's 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, 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.

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.

Since establishing the DSA and its P&Ps, CDII launched 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 nonprofit associations to deliver DxF-related education and training in 2023. Through its Signatory Grant program, CDII awarded more than $40 million across 790 DxF signatories to support the 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 QHIO 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. After signing the DSA, Participants are required to complete the PD as a means of communicating to other Participants their preferred means of sending and receiving data.

Overview of Roadmap Structure

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

The DxF Roadmap first acknowledges several considerations that have implications spanning multiple priority areas. The Roadmap then introduces and describes specific recommendations for each of six identified DxF priority areas (or "pillars"). The six priority areas are:

- Event Notification
- Social Service Data Sharing
- Consent Management
- Public Health
- Impact Measurement
- Participant Engagement

Discussion of each pillar includes a description of:

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

These priority areas were selected for their critical role in the DxF and California's health and social service data ecosystem, as well as for their alignment with other CalHHS priority initiatives. While not exhaustive of data exchange needs in the state, a focus on these pillars will help drive meaningful improvements in the ways data is accessed, used, and shared across a diverse set of entities.

Each pillar is in a different stage of planning and implementation. As a result, some recommendations differ in specificity and granularity. As such, the Roadmap describes actions for advancing CDII's data exchange priorities at a point in time. As the Roadmap is implemented, it will need to be updated to reflect implementation progress, incorporate any newly identified use-case priorities, align with existing and emerging data exchange initiatives and standards, and respond to an evolving data exchange landscape.

Together, the recommendations described in this Roadmap 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.[1]

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[1] CDII has also published a separate, **DxF Roadmap Companion Document** with supplementary background on select components of the main DxF Roadmap document. The Companion Document provides additional content on DxF Roadmap priority areas and cross-pillar considerations for interested readers (e.g., discussion of nationwide and state models for Event Notification, a review of relevant privacy law) as well as a glossary of terms. All recommendations and descriptions of actionable steps are included in the main DxF Roadmap document.

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 four cross-pillar topics: QHIOs; Privacy; Identity Management, and Behavioral Health.

Qualified Health Information Organizations

QHIOs are entities designated by CDII to facilitate the secure exchange of HSSI and are important enablers of data exchange among DxF Participants. QHIOs help DxF Participants generate and respond to information requests; send and receive test results and referrals; and solicit and forward event notifications of admissions or discharges.

Many recommendations in the DxF Roadmap involve QHIOs and the QHIO Program. 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. QHIOs can drive consistency, efficiency, and standardization to enable statewide exchange. Specific connections between the QHIOs and DxF Roadmap pillars are described in Appendix I.

Privacy

The legal framework governing data privacy in California is complex. The DxF Roadmap aims to help health and social service organizations navigate the various state and federal regulations that protect individual privacy while enabling secure exchange of HSSI, which requires robust data privacy safeguards to protect sensitive information. Many of the Roadmap pillars include recommendations to develop guidance, policies and procedures, technical standards, and service models. Federal and state data privacy and security laws and regulations will guide the development of these materials.

Comprehensive background on the laws and regulations governing data privacy is provided in the Roadmap Companion Document, as well as the State Health Information Guidance (SHIG), Data Sharing Authorization Guidance 2.0 (DSAG), and DSAG toolkits.

By prioritizing compliance with privacy rules and the protection of sensitive information, the DxF Roadmap aims to promote secure and effective information sharing while maintaining the highest standards of data privacy and security for individuals across California. Specific connections between privacy and DxF Roadmap pillars are described in Appendix IIII.

Identity Management

Identity management is necessary to implement many of the recommendations within the DxF Roadmap. A comprehensive identity management strategy includes several key elements to ensure secure, efficient, and compliant handling of individual identities, including:

1. **Identity assurance** - 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** - 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 accessing the data. 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 uses person attributes such as name, date of birth, address, phone number, or unique identifiers to establish a digital identity associated with the same real person across systems. Record linking links records, such as items of HSSI, belonging to the same real person into a single, consolidated record using these same person attributes. Person matching may use 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 by matching identities associated with different elements of health and social services information. Reliable person matching and record linking are foundational to implement many of the recommendations within the DxF Roadmap.

The DxF Roadmap recommends the following activities to ensure a robust identity management strategy:

- Revisit and update the DxF Strategy for Digital Identities to detail identity assurance, access management, and person-matching capabilities needed to support Event-Based Exchange, social service data use cases, consent management services, and public health data use cases.

- Update the Technical Requirements for Exchange Policy and Procedure, and consider developing additional DxF P&P, to detail technical standards and business requirements to support consent management services and other pillar needs.
- Engage the Office of Technology and Solutions Integration (OTSI), the California Department of Technology (CDT), the California Department of Health Care Services (DHCS), and other stakeholders on updates to the DxF Strategy for Digital Identities and DxF P&Ps

Behavioral Health

California 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,[2] while approximately one in 10 Californians over age 12 have struggled with a substance use disorder (SUD) in the past year.[3] Despite the prevalence of behavioral health needs, individuals are not consistently getting the care they need, with nearly two-thirds of adults with a mental illness not receiving treatment[4] and similar rates of missed care among commercial plan members with new episodes of alcohol or other drug dependence.[5] The burden of behavioral health needs is also unevenly distributed, with disproportionate impacts to vulnerable populations based on race, income, and incarceration status.[6,7]

CalHHS and the Administration more broadly have made a series of investments to support those living with mental health and substance use disorders.[8] 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

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[2] California Health Care Foundation. Mental Health Almanac 2022. July 2022. https://www.chcf.org/wp-content/uploads/2022/07/MentalHealthAlmanac2022.pdf.

[3] California Health Care Foundation. Substance Use Disorder Almanac 2022. January 2022. https://www.chcf.org/wp-content/uploads/2022/01/SubstanceUseDisorderAlmanac2022.pdf.

[4] California Health Care Foundation. Mental Health Almanac 2022. July 2022. https://www.chcf.org/wp-content/uploads/2022/07/MentalHealthAlmanac2022.pdf.

[5] California Health Care Foundation. Substance Use Disorder Almanac 2022. January 2022. https://www.chcf.org/wp-content/uploads/2022/01/SubstanceUseDisorderAlmanac2022.pdf.

[6] Ibid.

[7] California Health Care Foundation. Mental Health Almanac 2022. July 2022. https://www.chcf.org/wp-content/uploads/2022/07/MentalHealthAlmanac2022.pdf.

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

Behavioral Health Initiative (CYBHI), Medi-Cal Mobile Crisis and 988 expansion, and the Behavioral Health Continuum Infrastructure Program (BHCIP).[9]

The effective management of behavioral health conditions relies on accurate, timely, and secure data exchange. However, the behavioral health system faces unique challenges in achieving seamless exchange of HSSI, including few opportunities historically to participate in HIT incentive programs; lower rates of electronic health records (EHR) adoption than their physical health peers; uncertainty about the risk and legal implications for sharing sensitive SUD information; and a more diverse range of actors, each with varying capabilities and resources to support data exchange.[10] 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. Specific connections between behavioral health and DxF Roadmap pillars are described in Appendix III. 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.

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

[10] 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.

PILLAR #1

Event Notification

Introduction

Background of Issues

Health information sharing, especially when accomplished through nationwide networks and frameworks, is conducted almost exclusively through query-based document exchange. For example, query-based exchange is the only method supported so far by the Trusted Exchange Framework and Common Agreement (TEFCA). This exchange method is dependent upon the recipient of new health information suspecting that additional information exists that would benefit a patient's care and knowing where to obtain it or broadcasting a request to all network participants.

The Centers for Medicare & Medicaid Services (CMS) EHR Incentive Program established delivery of health information for certain health care events, such as sending discharge summaries to a patient's primary care provider (PCP) upon discharge from a hospital or emergency department (ED), as a necessary criterion to demonstrating the meaningful use of EHRs. Still, exchange continues to be dominated by query-based exchange with many providers rejecting unsolicited information delivery as a source of information overload.

The DxF established notification of admissions and discharges as a required exchange type for hospitals and EDs that are DxF Participants. DxF Participants must request notifications and therefore may choose to limit notifications to those patients for whom closer monitoring of health events may be necessary. Recipients of a notification may then follow up by requesting additional details using existing query-based exchange mechanisms with certain knowledge that additional health information exists and which DxF Participant can supply it. 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

In 2020, the Centers for Medicare & Medicaid Services Interoperability and Patient Access Final Rule established requirements for hospitals to provide admission and discharge notifications to PCPs and other providers identified by the patient.[11] The Final Rule, however, does not establish clear technical standards or an architecture for reporting admissions and discharges.

The DxF requires hospitals and EDs, and encourages skilled nursing facilities (SNFs), to send notifications of admissions and discharges to any authorized DxF Participant that submits a roster (a list of individuals) for which notifications were requested.[12] 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 rosters they will accept as well as the method, content, and format for sending notifications.

The DxF QHIO Program sets requirements for QHIOs to exchange rosters and notifications with each other. QHIOs are collaborating to develop consensus formats and mechanisms for exchanging rosters and notifications with other QHIOs. While the consensus standards QHIOs are voluntarily

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[11] "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).

[12] Technical Requirements for Exchange Policy and Procedure v1.0.1

adopting provide useful input into the DxF, QHIO consensus standards are not required of other DxF Participants.

In addition to preexisting solutions implemented by QHIOs, "private networks" comprising solutions to collect and communicate admissions and discharges have appeared within California and elsewhere. For example, some for-profit organizations had existing notification services that might focus on informing EDs of other ED admissions, and/or providing plans with better awareness of the admissions and discharges of their plan members. Unfortunately, the existing models, in the absence of a common statewide approach in California, contributes to a patchwork of solutions that may not interoperate with others. The diversity of business models and purposes for which the networks were created also contributes to stakeholder uncertainty.

No nationwide network or framework—including eHealth Exchange, Carequality, CommonWell Health Alliance, or TEFCA—provides a framework, an architecture, or technical standards for event notifications that the DxF can leverage. Notifications are not yet being discussed as a capability of Qualified Health Information Networks (QHINs) or TEFCA.

Issue to Be Addressed

Existing nationwide networks do not provide—and the DxF has not yet established—a coordinated method for those providing health care and social services to remain informed of significant events impacting the health of those they serve. This results in three critical issues to overcome to enable effective event notification.

Issue #1: Lack of Common Architecture. There is no overarching, common, statewide architecture for sending and receiving event notifications in California. The lack of a common architecture results in significant 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.

The lack of a common, statewide architecture creates fragmentation and presents a potentially untenable burden on DxF Participants who are required to send and want to receive event notifications across California. It also compounds the uncertainty regarding who may receive notifications containing protected health information and how individuals do or do not consent to notifications regarding events that impact their health.

Issue #2: Lack of Common Technical Standards. 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; and

- Those receiving notifications from many organizations using different formats and methods, including from some using methods that are inconvenient to integrate into their workflows.

For many providers, 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 on a roster to individuals that are the subject of an event. The DxF Strategy for Digital Identities[13] identified and the DxF Policies and Procedures established requirements for person matching, including those to be used in event notification. However, most DxF Participants have minimal access to technologies capable of effective person matching at the scale that might be required for statewide event notification.

Recommendations

Health 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 and is required of all DxF Participants.

This pillar recommends a new exchange type to be known as "Event-Based Exchange." Event-Based Exchange begins with the notification of significant events at health care and social service organizations as requested by a DxF Participant and as allowed by both applicable law and individual consent. In response to a notification, a DxF Participant may choose to retrieve more information about the event through query-based exchange.

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

Legislation, 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

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

innovation. Development and use of Fast Healthcare Interoperability Resources (FHIR) standards might be 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 the use of a common architecture** by aligning DxF P&Ps with the concepts and components of a common architecture for Event-Based Exchange. Explore legislative change that might allow mandated use of QHIOs, shared services, or other architecture components where such use promotes efficiencies, lowers administrative burden, and can align with national initiatives.

4. **Advance use cases beyond Notification of ADT Events** through discussions with CalHHS Departments and DxF stakeholders. Work with stakeholders to define and prioritize which activities constitute significant events that impact an individual's health and use cases that can 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.

   In developing use cases, care should be taken to ensure that consideration goes beyond delivering data to consider how it is incorporated into workflows and how it can be used to successfully transform care and improve patient outcomes.

Technical Infrastructure, Architecture, and Standards

1. **Establish a common 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; confirming that the requestor has authorization to receive notifications that may include protected health or other sensitive information; confirming that the individual has consented to notifications, if applicable; 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 shared services.

   The DxF will continue to leverage existing capabilities of nationwide networks and frameworks, including TEFCA, QHIOs and other intermediaries, and the DxF Participants in advancing the technical implementation of Event-Based Exchange. Efforts should enhance rather than compete or conflict with existing capabilities or business models.

   The burden on DxF Participants in conforming to the architecture, cost of participation, and sustainability of architectural components should all be considered in its development.

2. **Explore establishing shared 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 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",[14] adoption of any single shared or coordinated services may need to be voluntary. Exploration of shared or coordinated services must consider the cost of creating and maintaining them, as well as the cost for DxF Participants to utilize them effectively.

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 and consider the needs and limitations of supporting other DxF Participants such as social services and public health. Content standards for events and notifications should establish minimum necessary requirements to align with the first tenet of this pillar, to reduce burden on senders and receivers, and protect individual privacy, 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. Standards should align with the emerging focus on application programming interfaces (APIs) whenever possible.

   An important part of this effort is to clarify the requirements for attributes used to identify individuals in rosters, events, and notifications as necessary. As use cases expand, technical standards must be revisited and adjusted to address the limitations of new stakeholders and to meet the data requirements of new scenarios.

Financing, Contracting, and Operations

1. **Promote the use of shared services** by using CalHHS Department contractual levers and by reducing barriers to their use (e.g., cost reduction and simplified technical methods). Shared services must provide value to QHIOs and leverage the QHIO Program. Department contractual levers should require use of QHIOs, when appropriate (and not impose undue burden on QHIOs or DxF Participants) and significant voluntary use of QHIOs by DxF Participants to create critical mass use of shared services.
2. **Secure funding for initial development of shared 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 stakeholders, 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

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

applicability of FFP to create and sustain the shared services. Fund adoption of and connections to shared services through grants and contracts where possible.

3. **Explore models for operating shared services** by CalHHS, by a state Department, by a trusted nonprofit, by for-profit vendors, or other organizations with demonstrated DxF capabilities in such a way to ensure availability to any applicable DxF Participant. Explore governance models and identify sustainability models to reduce dependence upon the general fund and FFP.

Dependencies on Other Pillars

1. 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, is **dependent upon common, shared identities or robust person matching** as a prerequisite to success. The DxF Roadmap Cross-Pillar Considerations for Identity Management recommends implementing a comprehensive identity management strategy. Activities in pursuit of this goal, such as developing a common statewide person matching service or statewide master person index accessible by all DxF Participants, would benefit 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 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 to share notifications containing information on service needs sensitive to the client to maintain client trust.

    The DxF should create or update guidance[15] on when individual consent is required under applicable law, recognizing that HIPAA and California state law do not require patient consent for disclosure of protected health information for some purposes and that 42 C.F.R. Part 2 establishes additional consent requirements for some DxF Participants. It is important to understand the concerns of individuals and DxF Participants for protecting individual privacy while establishing Event-Based Exchange utilizing stakeholder outreach, town halls,

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[15] The State Health Information Guidance (SHIG) is an example of guidance available today that might be updated to address additional concerns and use cases.

or survey tools. The DxF may consider developing privacy controls beyond what is required by applicable law.

3. **Including social services in event notification will require investment of**:
    - Time and effort, to develop important use cases, establish data requirements and standards, and establish processes to obtain and communicate consent for the sharing of sensitive and protected health information;
    - Funding that leverages community information exchanges (CIEs) and social health information exchange capabilities emerging in California; and
    - Technical assistance and training, to help educate DxF Participants on the value and role of including social services in event notification, implementing robust consent processes, and enabling notifications within social services organizations.

Scenarios/Use-Cases

DxF identified an initial use case in Notifications of ADT Events already embodied in DxF Policies and Procedures. 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. Other 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:

1. Communicating encounters with specialists providing care for a chronic condition (e.g., cardiologist, pulmonologist) to PCPs or health plans;

2. Communicating discharges from a hospital and transfers to another facility to family caregivers as required by SB-675;[16]
3. Communicating admissions to and discharges from a hospital or ED to housing providers and Continuum of Care initiatives;
4. Communicating transfer events and other intra-facility events to health plans, including Medi-Cal plans, to aid with utilization determination;
5. Communicating (de-identified) ED admissions and chief complaints to the California Department of Public Health (CDPH) and/or local health jurisdictions (LHJs) to support syndromic surveillance;
6. Communicating (identifiable) reportable conditions to CDPH and/or LHJs to support care coordination (see the Public Health pillar for more information);
7. Communicating events that impact older adults that may make them eligible for the Program of All-Inclusive Care for the Elderly (PACE) or CalAIM Home and Community-Based Services support;
8. Communicating life events (e.g., births, deaths, loss of employment, changes in housing status, and release from incarceration) that change eligibility for other benefits to agencies that provide those benefits; and
9. 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.

Development of use cases, exploration of the cost-benefit of various use cases, and continual awareness of the potential for alert fatigue will be critical to the successful development of a common architecture and technical standards to support Event-Based Exchange.

Stakeholders have identified that event notification is not simply a technical issue to be addressed by a technical solution. The workflows of those that receive notifications must be considered. 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.

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[16] SB 675, Liu. Hospitals: family caregivers signed by the Governor and filed with Secretary of State October 4, 2015.

Actionable Steps

Legislation, Regulations, Policies, and Guidance	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. Discuss how best to integrate Event-Based Exchange into clinical and social services workflows.[17] Develop guidance on consent requirements for sharing protected health and other sensitive information through notifications to DxF Participants that are not HIPAA Covered Entities.	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. Promote notifications as a component of nationwide networks and initiatives. Update guidance on consent requirements for new use cases.	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. Promote notifications as a component of nationwide networks and initiatives. Update guidance on consent requirements for new use cases.
Require the Use of Minimum Technical Standards	Amend DxF P&Ps to include new event notification standards. Amend DxF P&Ps as necessary to clarify attributes of digital identity for person matching. Promote development and adoption of best practices through DxF Sandbox and other activities.	New event and notification standards become effective. Expand DxF P&Ps to include new use cases. Promote development and adoption of best practices through DxF Sandbox and other activities.	Expand DxF P&Ps to include new use cases. Promote development and adoption of best practices through DxF Sandbox and other activities.

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[17] Discussion of use cases, especially those surrounding social services, should include members of the Department of Health Care Services and consider the goals of CalAIM.

Legislation, Regulations, Policies, and Guidance	CY 2025	CY 2026	CY 2027
Advance the Use of a Common Architecture	Explore legislative changes that might allow mandated use of common architecture components such as QHIOs or shared services.	Amend DxF P&Ps to align with a common architecture. Explore mandating use of common architecture components in amendments to DxF P&Ps.	
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 (ongoing).	Work with Departments, QHIOs, DxF Participants, and other stakeholders to define, describe, and communicate new use cases and data requirements for Event-Based Exchange (ongoing).	Work with Departments, QHIOs, DxF Participants, and other stakeholders to define, describe, and communicate new use cases and data requirements for Event-Based Exchange (ongoing).

Technical Infrastructure, Architecture, and Standards	CY 2025	CY 2026	CY 2027
Establish a Common Architecture for Event-Based Exchange	Develop initial architecture for Event-Based Exchange in collaboration with QHIOs, Departments, DxF Participants, and other stakeholders.	Revise architecture to reflect learnings and shared service development details. Explore alternatives to roster-based requests, such as subscription models. Ensure architecture enables delegation to those responsible for follow-up activities and enables individual workflows.	Revise architecture to reflect learnings and shared service development details. Ensure architecture enables delegation to those responsible for follow-up activities and enables individual workflows.

Technical Infrastructure, Architecture, and Standards	CY 2025	CY 2026	CY 2027
Explore Shared or Coordinated Services Procurement and implementation actions may be cancelled if appropriate solutions are not forthcoming.	Complete and evaluate RFI for shared roster service. Procure vendor or award grant for roster service and begin implementation. Leverage strategy for digital identity to support statewide person matching for rosters, events, and notifications.	Shared roster service begins operation. Shared roster service utilizes statewide identity strategy for person matching. Complete RFI for shared event routing and notification service. Procure vendor or award grant for event notification service and begin implementation.	Shared event notification service begins operation. Leverage Impact Measurement to evaluate the impact of shared services.
Establish Minimum Technical Standards	Establish initial standards and format for event notification.	Establish initial standards and format for rosters based on shared roster service. Explore adding standards for subscription-based requests for notifications. Evaluate need for and implement standards adjustment based on architecture changes. Evaluate need for and implement standards adjustment based on new use cases.	Evaluate need for and implement standards adjustment based on architecture changes. Evaluate need for and implement standards adjustment based on new use cases.

Financing, Contracting, and Operations	CY 2025	CY 2026	CY 2027
Promote the Use of Shared Services		Require that QHIOs use a shared roster service. Explore and establish incentives for other DxF Participants to use shared services not mandated as a result of legislative change.	Require that QHIOs use shared event routing and notification service. Explore and establish incentives for other DxF Participants to use shared services not mandated as a result of legislative change.
Secure Funding for Initial Development of Shared Services Funding might include grants, state contracts, federal financial participation, sustainable business models, or other mechanisms to be determined.	Secure funding to develop shared roster service. Establish sustainability plan for shared roster service.	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 Shared 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 Sharing

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.”[18] Addressing SDOH is crucial to advancing health equity, improving quality of care, and achieving better health outcomes for all Californians. 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.”[19] The robust exchange of social services data between clinical care providers and community-based organizations(CBOs) 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

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[18] 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.

[19] 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.

exchange of SDOH information, though this is still a nascent domain with limited examples at scale.[20]

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 connect with all health and social service providers. In addition, models of social service data infrastructures range from simple to sophisticated, from 2-1-1 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 nonprofit 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.

Goal

The goal of the DxF Roadmap social service data sharing pillar is to establish scalable social service data sharing to connect individuals to the programs and services they need and enable seamless and timely 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 trusted relationships with local social service providers. The point here is that social and health care coordination 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 2-1-1 systems, CIEs, county services, and HIOs.
3. Where possible, align with and leverage peer state and federal best practices for social service data sharing, 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 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.

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[20] 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

Landscape

Summary of Current State

In California, social services span beyond state or federal government-funded programs and are often administered by counties and a range of CBOs. In addition, there is a wide range of longstanding community-based systems designed for different purposes, such as program and financial accountability, local community benefit, service navigation, and care coordination for specific populations. As a result, community systems have historically lacked the ability to interoperate effectively, thereby limiting their capacity to provide a comprehensive understanding of client needs.

Issue to Be Addressed

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 this data and limited experience with health and social data sharing at scale, there is also apprehension from stakeholders to release and share this information without clear insight into who will receive and access the information and how it will be used.

The lack of comprehensive social service data sharing also imposes a significant burden on individuals, families, and the system writ large. Individuals, families, and referring providers 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. Additionally, eligibility and case management functions for these programs have their own rules that govern disclosure, resulting in inefficient and duplicative administrative processes. A consistent approach that supports the sharing of 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. While HIPAA allows for most PHI to be shared, certain federal and state laws require individual consent to share sensitive data. California, like most other states, lacks a consistent framework and infrastructure to support a scalable consent management architecture.

Recommendations

Many efforts are underway to share HSSI, some driven by CalAIM initiatives, and other state, county, and local priorities. Without a 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, the 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, the 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 data sharing use case pilots over the next three years. Creating a system that will scale will take time, and efforts are already underway in support of CalAIM; however, the intent of DxF is to go beyond Medi-Cal members and provide a structure that can better serve all Californians.

In 2024, the California Department of Social Services (CDSS) and CDII convened program leaders to develop an affirmative vision for the role of social services data exchange to support connection to available services and benefits starting with 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 with the intention to expand into new priority areas based on CalHHS program and stakeholder priorities. 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.

Legislation, Regulations, Policies and Guidance

1. **Establish social service data exchange guidance.** CDII will assess existing social service data sharing requirements to identify barriers that could hinder data sharing across various programs. For example, the Having a Child and Early Childhood priority area 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 DxF 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 guidance that supports use case transactions and leverages existing data exchange standards including:
    - **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. 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 expanded upon. For example, the Preventing and Interrupting Homelessness priority area 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, the DxF would work with other standard setting bodies to expand libraries as needed and continually align with national data interoperability efforts.

- **Outlining system capabilities** needed to enable effective data exchange 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, and system performance.

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 CIEs, HIOs, enterprise exchanges using expanded EHR and population health tools, niche private vendors such as closed loop referral systems, and modernized social service data systems in California. This will include a deeper examination into the potential role of QHIOs in social and health information sharing.

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 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 Role in Enabling Social/Health Data Sharing

1. **Establish scalable identity and consent management capabilities**. Effective information sharing about individuals and families requires accurate identity matching. These services can enable widespread, dynamic, authorized sharing of protected social service information, accurately documented and attributed to the right individual.

Actionable Steps

Legislation, Regulation, Policies, and Guidance	CY 2025	CY 2026	CY 2027
Provide Social Service Data Exchange Resources and Guidance	Develop early implementation plans to address data exchange needs	Continually work to address regulatory barriers to enable the exchange of	If appropriate, develop DxF Policies and Procedures pertaining to social service data

Legislation, Regulation, Policies, and Guidance	CY 2025	CY 2026	CY 2027
	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. Work with stakeholders to identify additional priority use cases beyond the three initial priority life events.	minimally viable data. This may include work at the federal level in alignment with ASTP/ONC with social service programs and their IT vendors.	exchange technical requirements.

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 data exchange learnings and constraints and update guidance.	If appropriate, develop social service data exchange technical requirements for specified use cases.

Technical Infrastructure, Architecture, and Standards	CY 2025	CY 2026	CY 2027
Define a Vision for Developing Statewide Capabilities for Social and Health Data Exchange	Work with technical advisors with knowledge of existing system capabilities to draft a vision for how existing systems can connect to support scaled social service data sharing in California.	Expand and refine the social service data sharing vision to include data exchange and, where appropriate, provide guidance to support the implementation of system capabilities to achieve this vision.	If appropriate, develop and release DxF P&Ps to support adoption of system capability requirements.

Financing, Contracting, and Operations	CY 2025	CY 2026	CY 2027
Identify State and Federal Funding Sources	Identify existing funding sources that support data systems and sharing to uncover potential redundancies and opportunities to streamline and align efforts.	Based on learnings from the gap assessment, outline available state and federal funding sources to support data sharing.	

PILLAR #3

Consent Management

Introduction

Background Of Issues

The secure exchange of HSSI is essential to support whole-person care. While HIPAA allows for most PHI to be shared for the purposes of treatment, payment, or health care operations without requiring an individual's consent, certain federal and state laws require individual consent to share sensitive data, such as SUD information, which is protected by 42 C.F.R. Part 2 (hereinafter referred to as Part 2).[21]

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 organizations to promote care coordination. Managing consent preferences across multiple organizations is complex and requires adherence to strict federal and state privacy laws and regulations. The liability and potential legal repercussions associated with privacy violations or unauthorized release of this information create real and perceived barriers for organizations that participate in the exchange of protected information.

When implementing a consent management strategy, it is essential to consider "meaningful consent" practices requiring providers to inform individuals of 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.[22] A consent management strategy must consider how to inform and educate both individuals and the organizations requesting their consent.

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

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

Goal

The goal of the DxF Roadmap consent management pillar is to develop a consent management strategy that allows individuals to provide, update, and revoke their consent to securely share protected HSSI between their health 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 information is shared by ensuring consent management systems are accessible and support meaningful consent.
2. Prevent potential harms that may be caused by inappropriate sharing of sensitive data.
3. Streamline consent management processes without interrupting existing community data exchange capabilities and local trusted relationships with 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 and is adaptable to the needs and capabilities of local/regional data exchange and their participants.

Landscape

Summary Of Current State

California's consent management landscape is complex and fragmented, with organizations facing challenges navigating the various rules and consent forms to enable the exchange of protected HSSI. Behavioral health providers often struggle to interpret and adhere to privacy rules governing SUD data. As a result, many providers do not share SUD data with other organizations, even when it is legally permissible and could support better care coordination. Moreover, consent management practices vary across health and social service providers that may use paper forms, as well as electronic systems such as EHRs, HIOs, and CIEs.

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 including the SHIG,[23] DSAG,[24] and DSAG Toolkits.

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[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.

In 2023, DHCS piloted the Authorization to Share Confidential Medi-Cal Information (ASCMI) tools[25] in three counties to facilitate the exchange of protected HSSI about Medi-Cal members. The ASCMI tools included a standard release of information form and regional consent management services designed to simplify the process of obtaining and managing consent. The feedback from the pilot was promising, and DHCS is refining the ASCMI tools.

At the federal level, several standards, specifications, and APIs have been developed to support consent management. 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.

Issue to Be Addressed

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, and technical limitations. 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 extensive set of federal and state rules that govern the exchange of sensitive information make it challenging to develop consent management policies that satisfy all parties; especially when it pertains to rules governing the sharing of SUD treatment information protected by Part 2. The complexity of these rules creates uncertainty and perceived risks for organizations who maintain it. This leads to organizational siloes, where institutions elect not to share information due to internal policies, privacy concerns, perceived risk, and 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 platforms, and other electronic documentation systems lack the capability to store, manage, and track individual consent preferences. Additionally, most HIOs, 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 standard consent form, which leads to inconsistencies in tracking and managing consent across different organizations, systems, and regions. These technical challenges limit sharing of consent preferences, resulting in information siloes and uncoordinated care.

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[25] California Department of Health Care Services, "ASCMI CalAIM," 2023, https://www.dhcs.ca.gov/CalAIM/Pages/ASCMI-CalAIM.aspx

Recommendations

The proposed approach supports the development of a scalable consent management architecture, along with a set of services, DxF Policies and Procedures, and guidance to support implementation across all health and social services providers in California.[26]

Legislation, Regulation, Policies, and Guidance

Establish use cases, guidance, and strategies to support implementation of consent 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, CDSS, 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. **Expand upon data sharing and consent toolkits being developed by DHCS and CalHHS.** Toolkits will depict real-world data sharing and consent management scenarios, answer frequently asked questions, and provide practical guidance to those on the ground implementing consent management processes. Data sharing toolkits should focus on priority use cases, including bidirectional data exchange for, 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 Part 2 and non- Part 2 entities.
    c. Improving care coordination and health insurance eligibility determination and enrollment for individuals involved in the criminal legal system.
3. **Establish DxF consent management Policies and Procedures** that promote consent management services and architecture and ensure compliance with federal and state privacy laws and regulations. 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** focused on increasing awareness, understanding, and benefits of consent management processes among patients, health and social service providers, county health and privacy officers, and other stakeholders. This will require coordinating with DHCS, CDSS, and other CalHHS departments to support education, training, and technical assistance for organizations to effectively implement and utilize consent management services. These consent management resources will cater to diverse audiences and should be accessible and available in multiple languages.
5. **Develop a scalable consent management strategy** that builds upon DHCS' work, while expanding the scope of eConsent services to encompass all health and social service

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[26] CDII is exploring whether to pursue a statewide or federated approach to consent management services and will engage a wide range of stakeholders to determine the approach.

organizations in California. The strategy will include input from DHCS, OTSI, CDT, CDSS, county health and privacy officers, health and social services organizations, and other stakeholders. It will also include considerations for ongoing management, governance, and sustainability of statewide consent management services.

Technical Infrastructure, Architecture, and Standards

Leverage DHCS's ASCMI eConsent service initiatives to establish a scalable architecture of consent management services that can be implemented across all statewide health and social services organizations for all Californians.

1. **Establish an architecture for consent management services** that aligns with DHCS's work to advance the ASCMI eConsent concept. The architecture will lay the groundwork for services that provide individuals with access to consent management services, allowing individuals to provide, modify, and revoke their consent. It will consider storage and management of consent management preferences and notification capabilities that provide updates to individual consent preferences, changes in health plan coverage status, expired consent, and other events.
2. **Require use of national standards**, which may include HL7 classifications, implementation guides, FHIR resources, TEFCA, and other emerging federal standards through amendments of DxF Policies and Procedures.
3. **Support local implementation** through regional health and social service information exchange organizations and QHIOs that build upon existing local initiatives and provide education and technical assistance for the adoption of consent management services.

Financing, Contracting, and Operations

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

1. **Secure funding for consent management services**, which may include supporting the development of a DHCS Advance Planning Document 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 consent 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 consent management services. Use requirements to support procurement of vendors.

4. **Coordinate with departments to incentivize use of consent management services.** Initiatives such as the BH-CONNECT incentive should be established to adopt and use consent management services.

Actionable Steps

Legislation, Regulation, Policies, and Guidance	**CY 2025**	**CY 2026**	**CY 2027**
Consent Management Use Case Development	Draft and publish an initial set of consent management use cases.	Update initial use cases. Draft and publish a second set of consent management use cases.	Update use cases as needed.
Guidance and Toolkit Development	Develop an initial set of data sharing guidance toolkits.	Support updates to the SHIG and/or data sharing guidance toolkits to include additional use cases.	Update toolkits with the second set of use cases.
DxF Policies and Procedures	Develop DxF Policies and Procedures for consent management, services, aligning requirements with DHCS's ASCMI eConsent services and incorporating stakeholder feedback.	Develop DxF Policies and Procedures for consent management, services, aligning requirements with DHCS's ASCMI eConsent services and incorporating stakeholder feedback.	Update DxF Policies and Procedures to address additional use cases, as needed.
Education and Outreach	Develop an education and outreach campaign to support training and technical assistance for ASCMI consent tools (ongoing).	Develop an education and outreach campaign to support training and technical assistance for ASCMI consent tools (ongoing).	Develop an education and outreach campaign to support training and technical assistance for ASCMI consent tools (ongoing).

Technical Infrastructure, Architecture, and Standards	**CY 2025**	**CY 2026**	**CY 2027**
Architecture for Consent Management	Coordinate with DHCS, other departments,	Partner with DHCS, CDSS and other	Partner with DHCS, CDSS and other

Technical Infrastructure, Architecture, and Standards	CY 2025	CY 2026	CY 2027
	QHIOs and other stakeholders to develop architectural and business requirements for consent management services.	departments to support implementation of consent management services.	departments to support implementation of consent 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	Identify opportunities to 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.

Financing, Contracting, and Operations	CY 2025	CY 2026	CY 2027
Secure Funding for Consent Management Services	Collaborate with DHCS and other departments to secure state and federal FFP funding for consent management services.	Identify an ongoing sustainability model for consent management services.	Identify an ongoing sustainability model for consent management services.
Develop Consent Management Service Requirements	Work with DHCS, other departments, QHIOs and other stakeholders to develop requirements for consent management services.	Update consent management service requirements to support additional use cases.	Refine requirements for enhanced consent management capabilities.
Support Identification of Vendors and Procurement	Partner with DHCS to identify and procure technical solutions for consent management services.	Support DHCS efforts to refine vendor requirements and system capabilities.	Support DHCS efforts to refine vendor requirements and system capabilities.
Develop Incentives	Coordinate with departments on the development of incentive programs, contractual requirements, bulletins, notices, and directives to encourage support of consent management services (ongoing).	Coordinate with departments on refinement of incentive programs, contractual requirements, bulletins, notices, and directives to encourage support of consent management services (ongoing).	Coordinate with departments on refinement of incentive programs, contractual requirements, bulletins, notices, and directives to encourage support of consent management services (ongoing).

PILLAR #4

Public Health

Introduction

Background Of Issues

The COVID-19 pandemic revealed significant shortcomings in the country's public health infrastructure due to historic underfunding, particularly in its outdated and siloed data systems. 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.[27]

Efforts by the U.S. Centers for Disease Control and Prevention (CDC) have made significant strides to improve data exchange between health care providers and public health agencies (PHAs). Notably, electronic case reporting (eCR) automates the submission of reportable condition data from health care providers to PHAs and significantly enhances the speed and accuracy of public health reporting. The CDC, in partnership with ASTP/ONC, is aligning data and system standards, e.g., standardized APIs to facilitate real-time data exchange for public health via the HL7 HELIOS FHIR Accelerator and the United States Core Data for Interoperability Plus (USCDI+).[28,29]

Much work, however, remains to integrate public health with the broader health care IT ecosystem. TEFCA, the ASTP/ONC initiative aimed at breaking down data silos across the country, has expanded its scope to include exchange of information for public health purposes, and authorizing

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27 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.

28 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.

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

PHAs to access and exchange health information through the TEFCA framework.[30,31] CDII will consider the evolving role that TEFCA and other nationwide networks play, recognizing that 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 (DxF, CDPH, TEFCA, CDC) to enable DxF 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 LHJs, each with their own system of record. For example, 59 of these jurisdictions use California Reportable Disease Information Exchange (CalREDIE) as their system of record for reportable conditions and are increasingly fed by CDC's eCR system (automated data flows vs. manual data entry). This is a concrete example of how federal, state, and LHJ data systems can share data electronically. The state now has a direct role in supporting hospital data connections to the CDC's national syndromic surveillance platform (NSSP BioSense) which helps detect potential public health threats by collecting and analyzing de-identified data from EDs. CDPH's Future of Public Health (FoPH) IT and Data Modernization initiatives, largely funded by the CDC, will modernize the state's public health ecosystem and support timely sharing of public health information with LHJs across these programs. This will include modernizing CalREDIE and the

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30 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.

31 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.

statewide immunization registry (CAIR2). The FoPH effort emphasizes resilient, adaptable, and equitable public health systems.[32]

Issue to Be Addressed

California's public health data systems face significant challenges due to fragmentation and an inflexible funding structure, which complicate efforts to standardize data sharing across various reporting requirements and systems. Despite these challenges, there are opportunities for enhanced interoperability through the roles of DxF, TEFCA, and other federal initiatives that support public health data exchange. The DxF will support California PHAs in advancing interoperable data exchange through specific use cases, such as electronic case reporting and syndromic surveillance, and by expanding guidance to incorporate federal standards and technical requirements. CDII will seek additional use cases to support public health data exchange efforts through the DxF, and streamline provider connectivity, starting with EHR interoperability. *For more detailed information, refer to the DxF Roadmap Companion Document.*

Recommendations

DxF Guidance to Support Public Health Use Cases

Based on experience from electronic case reporting implementation, the DxF should clarify how LHJs can access additional information electronically after receipt of the electronic initial case report (eICR) which includes a small set of core data elements and begins the care reporting process. 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 health information exchanges which often do 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+) and 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 the DxF and/or 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 additional use case intersections with the DxF in support of public health. Although CDII will not oversee the

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32 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.

allocation of funds for the implementation of use cases, it will play a supportive role in advocating for funding to support these efforts.

Actionable Steps

Legislation, Regulation, Policies, and Guidance	CY 2025	CY 2026	CY 2027
Play a Supportive Role in eICR Implementation via TEFCA	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.	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 2025/26 learnings, implement direct DxF and/or TEFCA participation by PHAs in California.
Investigate Opportunities for DxF to Support Syndromic Surveillance	Determine workplan (if any) for DxF support for syndromic surveillance. This likely would include guidance on event notification data exchange elements and potentially DxF P&Ps. Determine potential role, if any, of the QHIO program to support syndromic surveillance in CA.		
Work Across CDC, ASTP/ONC, CDPH and LHJs to Identify Other Use Case Intersections with the DxF	Identify guidance and/or policies required to support adoption of interoperability standards in alignment with public health system modernization. Areas of investigation will include: • API access to immunization	Identify guidance and/or policies required to support adoption of interoperability standards in alignment with public health system modernization. Areas of investigation will include: • API access to immunization	Identify guidance and/or policies required to support adoption of interoperability standards in alignment with public health system modernization. Areas of investigation will include: • API access to immunization records, use of bulk

Legislation, Regulation, Policies, and Guidance	CY 2025	CY 2026	CY 2027
	records, use of bulk FHIR for population reporting, • adoption of USCDI+ in support of public health reporting, and; • electronic access to vital record information. Based on CDPH priorities, proactively identify additional DxF technical guidance to support use cases, including minimum necessary data sharing requirements.	records, use of bulk FHIR for population reporting, • adoption of USCDI+ in support of public health reporting, and; • electronic access to vital record information. Based on CDPH priorities, proactively identify additional DxF technical guidance to support use cases, including minimum necessary data sharing requirements.	FHIR for population reporting, • adoption of USCDI+ in support of public health reporting, and; • electronic access to vital record information. Based on CDPH priorities, proactively identify additional DxF technical guidance to support use cases, including minimum necessary data sharing requirements.

PILLAR #5

Impact Measurement

Introduction

Background

The DxF establishes a clear vision for the exchange of Health and Social Services Information. Measurement of progress towards this vision 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 and leverage the DxF's impact on data exchange, health and social services delivery, and health outcomes to inform future DxF design considerations.

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

- Tracking DxF adoption, identifying opportunities to improve DxF participation;
- Identifying the volume and types of data exchange between various DxF Participants;
- Assessing DxF Participant satisfaction with the quality, timeliness, usability, and security of data exchange;
- Assessing the positive or negative impacts of data exchange on the delivery of health and social services, wellbeing, health outcomes, and health equity; and
- Sharing findings of the measurement program with stakeholders and the public via various mediums and platforms, including public meetings.

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 assess the DxF's impact on equity across the state's healthcare and social services sector to the extent feasible.
5. 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.
6. Where possible, Impact Measurement will aim to leverage and align with existing national and state data and reporting initiatives and requirements to maximize efficiency and minimize burden of data collection and reporting.

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 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 IAC meeting held in September 2024. In early 2025, these metrics will be expanded to include transaction volumes reported by QHIOs.

Issue to Be Addressed

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, wellbeing, 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 among DxF Participants (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 wellbeing 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 wellbeing, DxF Impact Measurement cannot detect causal relationships.

Recommendations

CDII will manage a phased approach to Impact Measurement.

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 Service Data Sharing, Consent Management, Public Health, and DxF Participant Engagement.

Legislation, Regulations, Policies and Guidance

1. **Align QHIO Program requirements and the impact measurement pillar of the DxF 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 technical resources required to collect, manage, and report Impact Measurement data.** 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 governance and advisory committees will receive regular 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 may also help future signatories see the value of the DxF.

   d. Californians will be able to access summaries of DxF metrics 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 1). CDII will review the domains and metrics with stakeholders to finalize the Phase 2 approach for implementation.

Table 1. Potential domains and measures for phase 2 of Impact Measurement

Domains	Metrics/Information
Transitions of Care	• Percent of discharges resulting in re-admission including average time to re-admission • Time from discharge/referral to receipt of services
Utilization	• 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 race, ethnicity, and language, disability, sexual orientation, and gender identity (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's impact on wellbeing 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 TEFCA's 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 2. Summary of Impact Measurement phases

Phase *(Dates)*	**Focus**	**Metrics**
Phase 1 (2024–2025)	Structure and Process	• **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 DxF Grants and QHIO programs (and other related efforts) reflecting the support offered to assist DxF Participants.
Phase 2 (2025–2026)	Process and Intermediate Outcomes	• **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	• **Quality:** Impacts to health and social service outcomes and wellbeing.

Actionable Steps

Legislation, Regulation, Policies, and Guidance	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).

Technical Infrastructure, Architecture, and Standards	CY 2025	CY 2026	CY 2027
Identify Technical Resources Required to Collect, Manage and Report Impact Measurement Data	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.

Financing, Contracting, Operations	CY 2025	CY 2026	CY 2027
***[Phase 1]* Finalize a Phase 1 Data Report and Share Findings**	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.	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.	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.

Financing, Contracting, Operations	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**	Discuss Phase 2 domains and metrics with the IAC. Work with stakeholders to identify and produce Phase 2 metrics.	Implement the confirmed Phase 2 approach for impact measurement. Update DxF reporting to include Phase 2 metrics.	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**		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.	Implement the Phase 3 approach. Assess the impact of the DxF on wellbeing and health outcomes and identify needs for 2028 and beyond, in partnership with the independent researcher vendor.
Engage Federal Partners, National Networks, and TEFCA's QHINs to Assess Opportunities to Collaborate on Impact Measurement	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	Assess Phase 1 and early Phase 2 metrics to inform DxF priorities and identify opportunities to support data exchange (ongoing).	Assess Phase 1 and 2 metrics to inform DxF priorities and identify opportunities to further support data exchange (ongoing).	Assess Phase 1 and 2 metrics to inform DxF priorities and identify opportunities to further support data exchange (ongoing).
Provide additional Impact Measurement to support other Roadmap pillars	As the DxF Roadmap pillars execute on their plans, partner with each team to identify metrics to support their assessment (ongoing).	As the DxF Roadmap pillars execute on their plans, partner with each team to identify metrics to support their assessment (ongoing).	As the DxF Roadmap pillars execute on their plans, partner with each team to identify metrics to support their assessment (ongoing).

PILLAR #6

Participant Engagement

Introduction

Background Of Issues

The DxF requires organizations specified in HSC § 130290 to become DxF Participants by signing the DxF 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.

Many mandatory signatories have not yet signed the DSA, and some mandatory signatory categories—including “physician organizations and medical groups” (POMGs)—are not clearly defined in statute, making it difficult to measure the total number of required DSA signatories. Meanwhile, the completion rate of DxF Participant Directory entries among signatories is significantly below 100% and there are major inconsistencies with how signatories have filled out their entries.

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 pillar’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. Requirements and support extended to DxF Participants should align with, to the extent feasible and reasonable, those of existing state and federal programs such as CalAIM and TEFCA.
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 January 2025, the DxF has over 2,500 signed DSAs representing over 4,400 DxF Participants.

Also as of January 2025, about 57% of all DSA signatories (2,510 out of 4,403) 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 3: DxF Signing Portal Records as of January 13, 2025

Participant Type (self-identified)	**Count of Organizations**
Acute Care Settings	414
Ambulatory Care Settings	1,879
Subacute Care Facilities	739
Plans	101
Ancillary Care	453
Pharmacy	19
Community-Based Organizations	435
Counties and County Departments	94
Emergency Medical Service Providers	45
Intermediaries (including QHIOs)	60
Not Selected	164
Total Participant Type Count	**4,403**

Issue to Be Addressed

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. Additionally, 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.

Recommendations

Legislation, Regulations, Policies and Guidance

1. Establish and expand definitions of mandatory signatories by:
    a. Pursuing and leveraging state legislative changes that 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 shares relevant case examples and identifies barriers to adoption, communication channels, and channel partners to reach non-compliant required signatories; and
        iii. Identifying and securing resources for partners to engage 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 direct DxF Participants to resources 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 TEFCA 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

Legislation, Regulation, Policies, and Guidance	**CY 2025**	**CY 2026**	**CY 2027**
Establish Trusted Denominators	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. Develop and submit a statewide communications plan.	Welcome Guide revisions and updates. Execute the statewide communications plan.	Welcome Guide revisions and updates. Refine 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 Impact Measurement	Continue measuring and refining success metrics as necessary.	Continue measuring and refining success metrics as necessary.

Legislation, Regulation, Policies, and Guidance	**CY 2025**	**CY 2026**	**CY 2027**
	strategy where possible.		
Accountability Framework	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.	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.	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.

Technical Infrastructure, Architecture, Standards	**CY 2025**	**CY 2026**	**CY 2027**
Infrastructure	Determine and implement upgrades to PD infrastructure.	Identify PD infrastructure outcomes.	Identify PD infrastructure outcomes.

Financing, Contracting, Operations	**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.

Appendix I. Connections between QHIOs and DxF Roadmap Pillars

Pillar	Connections to QHIO Program
Event Notification	• 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 Service Data Sharing	• QHIOs could potentially support local social service data sharing activities.
Consent Management	• QHIOs will be critical inputs to and implementers of an efficient and scalable consent management architecture. • 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	• 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	• 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	• 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).

Appendix II. Connections between Privacy and DxF Roadmap Pillars

Pillar	Connections to Privacy
Event Notification	Event notification policies must be developed to ensure that all notifications comply with federal and state privacy laws, including respecting individual confidentiality and consent rules.
Social Service Data Sharing	Social Service data sharing policies must consider federal and state privacy rules, and the DxF should develop appropriate policies and procedures aligning with these rules to support social service data exchange.
Consent Management	Privacy policies and procedures and guidance are considered as the development of the architecture is advanced to ensure appropriate and meaningful consent.
Public Health	The DxF should develop guidance, policies and procedures aligning with federal and state public health privacy laws.
Impact Measurement	Privacy considerations must be incorporated throughout the analysis of individually identifiable data sets to ensure individual confidentiality.

Appendix III. Connections between Behavioral Health and DxF Roadmap Pillars

Pillar	Connections to Behavioral Health
Event Notification	● Behavioral health providers should 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 Service Data Sharing	● Social service data sharing standards, guidance, and policies should be developed to support behavioral health providers - many of whom are CBOs and exchange social service data – in their participation in the DxF.
Consent Management	● Consent management use cases, toolkits, and educational resources that address the needs of behavioral health providers should be developed to support their participation in the DxF.
Impact Measurement	● 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	● Many behavioral health providers, such as provider organizations and acute psychiatric hospitals, are required signatories of the DSA. Outreach strategies, technical assistance and sections in the Welcome Guide relevant to their engagement are needed to support data exchange and compliance with DxF requirements.