

Data Exchange Framework Legislative Update

California Health & Human Services Agency

April 2022

Agenda

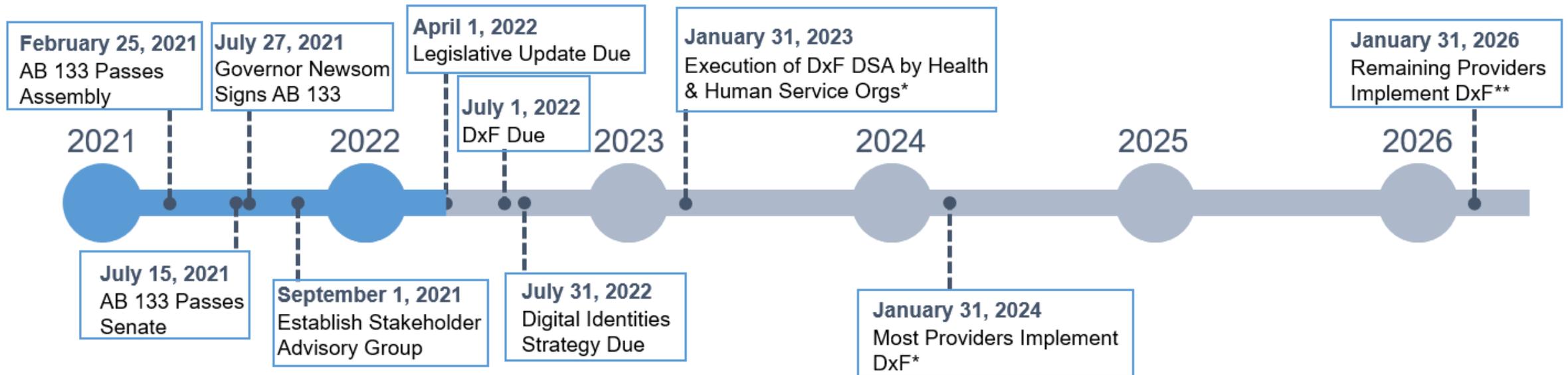
- **Data Exchange Framework Overview**
- **Data Exchange Framework Development Status Update**
 - Data Exchange Framework
 - Data Sharing Agreement and Policies & Procedures
 - Digital Identities Strategy
- **Data Exchange Framework Development Considerations and Next Steps**

Data Exchange Framework (DxF) Overview

DxF Statutory Requirements & Timeline

AB 133 put California on the path to building a Health and Human Services Data Exchange Framework (DxF) that will advance and govern the exchange of electronic health information across the state.

AB 133 Implementation Timeline



*General acute care hospitals, physician organizations and medical groups, skilled nursing facilities, health service plans and disability insurers, Medi-Cal managed care plans, clinical laboratories, and acute psychiatric hospitals. County health, public health, and social services providers are encouraged to connect to the DxF.

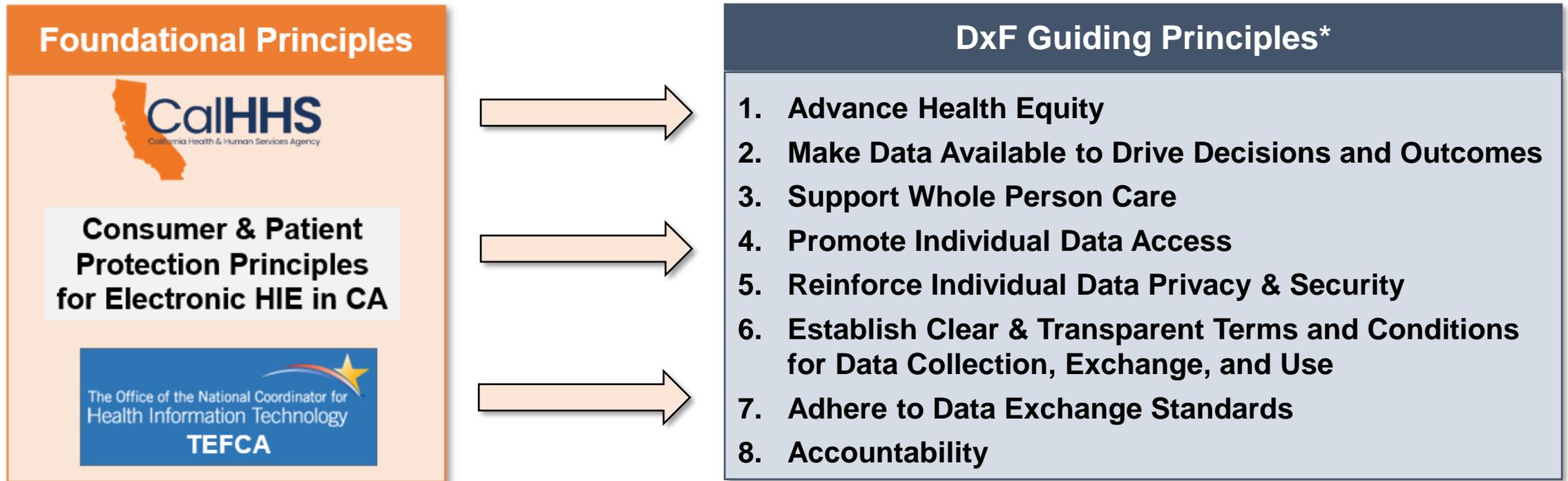
**Physician practices of <25 physicians, rehabilitation hospitals, long-term acute care hospitals, acute psychiatric hospitals, critical access hospitals, and rural general acute care hospitals with <100 acute care beds, state-run acute psychiatric hospitals, and nonprofit clinics with <10 providers

Vision for Data Exchange in California

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.

DxF Guiding Principles

The CalHHS DxF Guiding Principles, developed to align with other federal and CalHHS principles and established with extensive stakeholder input, will guide DxF design and implementation.



*The complete DxF Guiding Principles are available on the [CalHHS DxF website](#).

1. [CalHHS Guiding Principles](#).
2. [Consumer and Patient Protection Principles for Electronic HIE in CA](#).
3. [ONC's TEFCA Principles for Trusted Exchange](#).

Data Exchange Framework Development Status Update

DxF Components

AB 133, enacting Health and Safety Code § 130290, requires CalHHS to develop the following:

1. **Data Exchange Framework (DxF)**, designed to enable and require access to, or exchange of, health information among health care organizations through any health information exchange network, health information organization, or technology that adheres to specific standards and policies.
2. **Data Sharing Agreement and Common Set of Policies and Procedures** (included in DxF), outlining the standards for and governance of information exchange set forth by the DxF that many health care organizations would be expected to execute by January 31, 2023.
3. **Digital Identity Strategy**, a strategy for unique, secure digital identities capable of supporting master patient indices to be implemented by both private and public organizations in California.

Data Exchange Framework Development Status Update

Data Exchange Framework

DxF: Requirements

The DxF will include a single data sharing agreement (DSA), common set of policies and procedures, and the other components shown below.

Data Exchange Framework

Overview: 1 Vision 2 Guiding Principles 3 DxF Development

Landscape: 4 California Data Exchange Landscape

Issue Identification and Solution Development:



5 Model Scenarios and Identified Data Exchange Gaps

6 Recommended Standards, Policies, and Reforms

7 CA Data Sharing Agreement and Policies & Procedures

The DxF will define:

- Solutions to data exchange gaps, including health information technology capacity, data standards, and regulatory and policy barriers
- Ways to incorporate SDOH data, behavioral health and SUD data, and data related to underserved/ underrepresented populations
- Governance structures to guide future data policy discussions
- Mitigation strategies for privacy, security, and equity risks of expanded health data exchange

DxF: Advisory Group + Development Progress

AB 133 required CalHHS to convene a Stakeholder Advisory Group to advise CalHHS on health information technology issues included in the DxF.

Stakeholder Advisory Group

Purpose: The Advisory Group (AG) advises CalHHS in DxF development.

Roles: The AG advises and advances recommendations to the Secretary of CalHHS. It does not have decision-making authority.

Members: The AG is chaired by Dr. Mark Ghaly, Secretary of CalHHS and is composed of members from 27 stakeholder organizations and 14 state departments.

Status	DxF Development Step
✓	Convene DxF Stakeholder Advisory Group (AG)
✓	Convene AG Data Sharing Agreement Subcommittee
✓	Identify key data exchange gaps across technical infrastructure and standards, financing/business operations, and regulatory/policy domains
✓	Establish guiding principles for CA health and human services data exchange
✓	Provide feedback on options for resolving infrastructure gaps (HIT)
✓	Provide feedback on resolution options for standards and consumer access gaps
✓	Provide feedback on options for establishing governance
4/7	Continue discussion on governance and provide feedback on options for resolving regulatory/policy gaps
5/18	Provide feedback on draft DxF
6/23	Review final DxF
7/1	Deliver DxF

DxF: Emerging Approach and Key Concepts

Opportunities: HIT Infrastructure

The AG continues to consider and endorse recommendations to address key data exchange gaps. At its December meeting, the AG identified opportunities to address gaps in HIT infrastructure which have been advanced to CalHHS Secretary Ghaly for consideration.

1. **EHR Adoption**
 - **Opportunity 1:** Consider a Multi-Payer EHR Incentive Program
2. **Data Exchange Capacity at Many Health Care and Human Service Organizations**
 - **Opportunity 2a:** Consider a HIE On-Boarding Program
 - **Opportunity 2b:** Consider Qualifying Information Exchange Intermediary and Data Sharing Policies
3. **Event Notifications**
 - **Opportunity 3a:** Consider Policies that Expands Event Notification Requirements
4. **Intra- & Inter-Sector Data Exchange Capabilities**
 - **Opportunity 4a:** Consider Developing a Public Health and Human Services Data Exchange Capacity Building Program
 - **Opportunity 4b:** Consider Policies that Expand Human Service Data Reporting Requirements

Full details for identified HIT infrastructure gaps and opportunities can be found in Appendix I.

Gaps and Opportunities: EHR Adoption

Gap #1: EHR adoption is limited among some health care organizations, particularly those that did not have access to HITECH and other federal/state modernization funding (e.g., behavioral health, long term care facilities, correctional facility health, and small physical health providers); not all EHRs are certified or have capacity to exchange data using national standards.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the:*

- *Storage, maintenance, and management of health information. [§130290(c)(3)(B)(iii)]*
- *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Opportunities:

- A. Consider EHR Incentive Program:** Build on investments being made by the state to private payers to incentivize adoption of certified EHR technology (CEHRT) and, for non-HIPAA covered entities, qualifying clinical documentation technologies that support the collection, exchange, and use of electronic health information in accordance with state requirements.
- **Models:** U.S. HHS HITECH, NC [EHR Incentive Program for BH/IDD Providers](#), [NJ Substance Use Disorder Promoting Interoperability Program](#)
- B. Consider EHR Implementation Training & Technical Assistance:** Incentive programs can be coupled with technical assistance to support health care organizations' adoption of EHRs.
- **Models:** HITECH [Regional Extension Centers](#), DHCS CA [Technical Assistance Program](#)
- C. Consider Promoting Certified EHR Requirements in State Programs:** [Certified](#) EHR technology requirements can be incorporated into state contracting (e.g., Covered California, DHCS managed care, CalPERS QHP contracts); may be particularly important for advancing integrated behavioral health (see MACPAC June 2021 [reporting](#)).
- **Models:** Medicare [Quality Payment Program](#) (QPP)

Gaps & Opportunities: Data Exchange Capacity at Many Health Care and Human Service Organizations

Gap #2: Many health care and human service organizations have limited technological capacity to store, electronically share, and use health and human service information.

Relevant AB 133 Provision(s): *Identify which data beyond health information as defined in paragraph (4) of subdivision (a), at a minimum, should be shared for specified purposes between the entities outlined in this subdivision and subdivision (f).*

[§130290(c)(3)(A)] Minimum “health information” sharing requirements in AB-133 are defined for specific health care organization, but broadly include provider sharing of USCDI and “electronic health information” per Section 171.102 of Title 45 of Code of Federal Regulations, and payer sharing of data per federal Interoperability regulations.

Opportunities:

- A. Consider a Health and Human Service Organization HIE Onboarding and Technical Assistance Program.** A program can be established to provide funding, incentives, and technical assistance to help health and human service organizations securely exchange electronic health information to support onboarding to a qualifying data exchange intermediary in accordance with AB 133, DxF priorities and state requirements.
- **Models:** CA DHCS [California HIE Onboarding Program \(Cal-HOP\)](#), [TNC Tailored Care Management Capacity Building Program](#)
- B. Consider a Data Sharing Intermediary and Data Sharing Requirements Policy.** Policy can be established that leverages national programs that define data sharing intermediary qualifications and further specify additional state data sharing requirements pursuant to AB-133 that should be incorporated into the DxF Data Sharing Agreement.

Gaps and Opportunities: **Event Notifications**

Gap #3: Event notifications today are mostly limited to transitions from acute care facilities and are not widespread for housing, incarceration status and other important events.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in:*

- *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Opportunities:

- A. Consider Expanding Federal Alert Notification Requirements:** State policy and contracting requirements can be developed, extending the scope and scale of federal Interoperability and Patient Access Final Rule ([CMS-9115-F](#)) notification requirements to additional health and human service organizations.
- **Models:** FL Medicaid managed care plan [contracts](#) with required linkages to pre-booking sites for behavioral health assessments and potential diversion; AZ Medicaid managed care plan/justice system data [connections](#) and Medicaid requirements to support transitions; MI Medicaid [pilot](#) to identify homeless individuals by HMIS matching; CA WPC Pilot program [lessons learned](#)

Gaps & Opportunities: Intra- & Inter-Sector Data Exchange Capabilities

Gap #4: Some state, county and other local government public health and human service organization information systems have limited capabilities to electronically exchange timely and usable health information with health care organizations.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in...Linking, sharing, exchanging, and providing access to health information.[§130290(c)(3)(B)(iv)]*

[By] January 31, 2023, [CalHHS] shall work with the [CA] State Association of Counties to encourage the inclusion of county health, public health, and social services, to the extent possible, as part of the [DxF] in order to assist both public and private entities to connect through uniform standards and policies. It is the intent of the Legislature that all state and local public health agencies will exchange electronic health information in real time with participating health care entities... [§130290(c)(5)(E)]

Opportunities:

- A. Consider Upgrades to California County Health IT Infrastructure:** Leverage and expand federally funded programs to upgrade state and local public health IT infrastructure and to provide a glidepath for county health, public health, and social service entities to participate in information exchange.
- **Models:** CDC [Data Modernization Initiative](#) nationally and CA's ~\$300m allocation for public health modernization
- B. Consider Developing Public Agency Data Exchange Policy and Contracting Requirements.** Through policy (e.g., statewide HMIS reporting to centralized Homeless Data Integration System [[HDIS](#)] via [AB977](#)), procurement processes and contract amendments, public agencies could contractually obligate vendors to share information with health and human service organizations to advance goals envisioned by AB-133.
- **Models:** Merced and San Joaquin County [contracts](#) with EHR vendors serving their county jails

DxF: Emerging Approach and Key Concepts

Opportunities: Standards, Provider Identity Management, Consumer Data Access

At its January meeting, the AG identified opportunities to address gaps in data exchange standards, provider identity management, and consumer data access.

Discussion of policy and regulatory gaps and opportunities will take place during the April AG meeting.

1. Human Service and Demographic Data Exchange Standards and Capacity

- **Opportunity 1a:** SDOH data collection and use standards, requirements, and incentives
- **Opportunity 1b:** Demographic data collection and use standards, requirements, and incentives
- **Opportunity 1c:** Enhance cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care
- **Opportunity 1d:** Advance recommendations to federal government to improve demographic data collection nationally

2. Provider Identity Management

- **Opportunity 2a:** Expand upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule.
- **Opportunity 2b:** Require qualifying HIOs to participate in a federated provider identity management service

3. Consumer Data Access

- **Opportunity 3a:** Adopt policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions
- **Opportunity 3b:** Adopt policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use

Gaps & Opportunities: **Human Service and Demographic Data Exchange Standards and Capacity**

Gap #1a: National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of Social Determinants of Health (SDOH) and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.

Gap #1b: Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to social determinants of health, such as housing and food insecurity, into shared health information. [§130290(c)(3)(C)]*

Identify ways to incorporate data related to underserved or underrepresented populations, including, but not limited to, data regarding sexual orientation and gender identity and racial and ethnic minorities. [§130290(c)(3)(D)]

Opportunities:

A. Consider establishing SDOH data collection and use standards, requirements, and incentives. CalHHS should adopt the US Core Data for Interoperability (USCDI) Version 2 standards to facilitate consumer SDOH data collection, in addition to consumer race, ethnicity, language, sexual orientation, gender identity, social and behavioral risk information.

Standards may be paired with common data collection, data quality and performance reporting requirements and incentives through public and private payers to support system change. Data collectors and users may also require technical assistance to support new data collection and use practices.

Gaps & Opportunities: Human Service and Demographic Data Exchange Standards and Capacity

Opportunities *(continued)*:

- B. Consider establishing demographic data collection and use standards, requirements, and incentives.** Paired with the previous opportunity, California may work with private health care organizations to establish and require demographic data collection and reporting (e.g., race, ethnicity, sexual orientation, gender identity, disability status, etc.) in accordance with federal standards (e.g., CDC and OMB, USCDI v2.0), and ensure consistent and comprehensive demographic data collection across public and private entities.
- **Model:** [Connecticut's SB-1](#) required that state agencies and some health providers collect demographic data in standard categories aligned with U.S. OMB standards
- C. Consider enhancing cross-state agency data sharing efforts.** California may enhance its interagency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care. Data shared may include program enrollment, demographic, service utilization, and/or health and human service needs information captured by agencies and departments including DHCS (Medi-Cal), DPSS (Cal-Fresh), BCSH (HDIS), Covered CA, and CalPERS.
- D. Consider advancing recommendations to federal government to improve demographic data collection nationally.** Race and ethnicity data collection remain uneven across the health care data ecosystem and multiple federal standards also exist (e.g., HRSA for example does not align with USCDI v1 or v2). California should develop a process to advocate for and advance data standards that better align with national standards and fill data standard gaps that are needed to advance state priorities.

Gaps & Opportunities: Provider Identity Management

Gap #2: Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the: Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Opportunities:

- A. Consider expanding upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule.** California could require all signatories of the DxF DSA to maintain and update identity credentials. The requirement in CMS's Interoperability and Patient Access Final Rule ([CMS-9115-F](#)) that specified payers offer a public facing Provider Directory API using a FHIR-based API could be expanded to include:
1. All payers licensed in California, including Qualified Health Plans (QHPs); and
 2. DxF DSA signatories, such that all parties provide updated credentials to payers and to any qualifying health information exchange intermediaries with which they share data.
- B. Consider requiring qualifying HIOs to participate in a federated provider identity management service.** Implementing identity and master data management as a shared service can reduce individual organizational burden. The DxF can establish a set of requirements for qualifying HIOs that they deploy master data management approaches to identity management that include technical systems, processes, governance, policies, and standards to establish a consistent reference identity for individuals, the data attributed to them, the identity of providers, provider membership in organizations, and patients attributed to them.

Gaps & Opportunities: Consumer Data Access

Gap #3: Individuals consistently face challenges in accessing their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

Relevant AB 133 Provision(s):

- *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*
- *Identify how all payers will be required to provide enrollees with electronic access to their health information, consistent with rules applicable to federal payer programs. [§130290(c)(3)(I)]*

Opportunities:

- A. Consider policies to ensure consumers have meaningful access to their longitudinal health information.** Access to longitudinal health information across all health care organizations subject to AB-133 would allow consumers to make informed health decisions. Potential policies and requirements could include:
- Expanding federal information blocking and patient access API rules to all health care organizations subject to the DxF
 - Evaluating where California law governs consumers access to their longitudinal health information (e.g., [California Health and Safety Code 123110](#)) since the federal Information Blocking and Patient Access Interoperability rules defer to state law
 - Providing consumers with bi-directional access to their health information in a manner that accommodates their individual needs and preferences
 - Working with health care organizations to provide consumers with education and support on how to access, use, and update their health information
- B. Consider policies to ensure consumers understand how their health information may be used.** Potential policies and requirements could include review of and potential updates to state Fair Information Practices and development of practices to hold DSA participants accountable for participation in the appropriate exchange and use of consumer health information.
- Models:** The U.S. HHS Office of Civil Rights' [Individuals' Right under HIPAA to Access their Health Information 45 CFR § 164](#) and ONC's [2018 Model Privacy Notice](#) provide examples of clear guidance to inform consumers about data access and privacy policies.

Gaps & Opportunities: Regulatory and Policy (for April AG Meeting)

Gap: Numerous federal and state laws, regulations and policies that govern the exchange of physical, behavioral health, social and human services data create real or perceived barriers to sharing information that is necessary to inform whole person care and population health needs.

Relevant AB 133 Provision(s):

- *The DxF “shall align with state and federal data requirements including...applicable state and federal privacy laws related to the sharing of data...” [§130290(a)(3)]*
- *Address the privacy, security, and equity risks of expanding care coordination, **health information exchange**, access, and telehealth in a dynamic technological, and entrepreneurial environment, where data and network security are under constant threat of attack. [§130290(c)(3)(F)]*
- *Identify ways to incorporate relevant data on behavioral health and substance use disorder conditions. [§130290(c)(3)(E)]*
- *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Opportunities:

During the April meeting, the Advisory Group will consider potential opportunities to facilitate data sharing in accordance with the numerous federal and state laws, regulations, and policies that govern the exchange of different kinds of data.

DxF: Emerging Approach and Key Concepts

Governance

At its March meeting, the Advisory Group considered options for establishing governance of the Data Exchange Framework – a discussion that will continue in the April meeting.

Overview of the Draft Governance Model

1

Purpose and Goals of Governance Structure

2

Governance Legal and Contractual Framework

3

Core Governance Functions

Note: The governance model included in this presentation reflects the model that was reviewed with the Advisory Group during the March meeting. The model may change based on further discussions with the Advisory Group. The full model that was reviewed during the March meeting can be found [here](#).

1

Purpose and Goals of Governance Structure

Formalized Governance is needed to drive and oversee the successful implementation and ongoing refinement of the DxF and state HIE policies and procedures, programs and priorities.

DxF Governance Goals

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

Note: The governance model included in this presentation reflects the model that was reviewed with the Advisory Group during the March meeting. The model may change based on further discussions with the Advisory Group. The full model that was reviewed during the March meeting can be found [here](#).

Governance Legal and Contractual Framework

CDII, as an Office within CalHHS, would oversee implementation of the Data Sharing Agreement and enforce policies and procedures (P&Ps) and requirements for entities subject to AB 133's data sharing mandate.

1



Health and human service entities as defined in AB 133 will execute the DxF DSA with CalHHS/CDII.

2



Pursuant to the DSA, health and human service entities as specified in AB133 will share data with other health and human service entities in California.

3



The DSA will incorporate Policies and Procedures that DSA signatories would be required contractually to comply with.



4



In addition to the terms of the DSA, health and human service entities must also comply with other data sharing P&Ps and requirements, developed via the Governance Structure.

Note: The governance model included in this presentation reflects the model that was reviewed with the Advisory Group during the March meeting. The model may change based on further discussions with the Advisory Group. The full model that was reviewed during the March meeting can be found [here](#).

3

Core Governance Functions

1. Harmonization of state law with federal law	7. Program development and financing
2. Development of and modifications to DSA Policies and Procedures (P&Ps)	8. Identification and qualification of exchange intermediaries
3. Enactment of data sharing P&Ps and Requirements	9. Communications and education
4. Review of Federal standards and national efforts impacting data exchange	10. Ongoing review of DSA
5. Enforcement and monitoring compliance with P&Ps, requirements and guidelines	11. Coordination with other branches of state and local government
6. Dispute resolution	

Note: The governance model included in this presentation reflects the model that was reviewed with the Advisory Group during the March meeting. The model may change based on further discussions with the Advisory Group. The full model that was reviewed during the March meeting can be found [here](#).

Form of Governance (for April AG Meeting)

Governance Model Next Steps

- During the April meeting, the Advisory Group will consider a proposed governance structure to oversee implementation and ongoing refinement of the DxF, Data Sharing Agreement and Policies and Procedures.
- The governance structure will detail roles and responsibilities for state government and other stakeholders involved in DxF governance.

Data Exchange Framework Development Status Update

Data Sharing Agreement and Policies & Procedures

Data Sharing Agreement (DSA) and Policies & Procedures (P&Ps): Requirements

The Data Exchange Framework includes a single data sharing agreement and common set of policies and procedures that must also be established by July 1, 2022.

DxF Data Sharing Agreement and Policies and Procedures *Legislative Requirements*

- By July 1, 2022, AB 133 requires that CalHHS establish a Data Exchange Framework that includes a **single data sharing agreement (DSA) and common set of policies and procedures (P&Ps)** that will govern the exchange of health information.
- Section 130290 mandates that a broad spectrum of health care organizations **execute the data sharing agreement** by January 31, 2023, and **exchange or provide access to health information** with other mandated organizations by January 31, 2024.

DSA and P&Ps: Subcommittee + Development Progress

DSA Subcommittee

Purpose: The Data Sharing Agreement (DSA) Subcommittee advises CalHHS and the AG in the development of the statewide DxF DSA.*

Roles: The DSA Subcommittee advises and advances recommendations to the AG and does not have decision-making authority.

Members: The DSA Subcommittee is chaired by Jennifer Schwartz, Chief Counsel, CalHHS CDII and is composed of 20 members, including 4 members representing state departments.

Status	DxF DSA Development Step
✓	Convene DxF Data Sharing Agreement (DSA) Subcommittee and hold first meeting to discuss subcommittee charge and review other DSAs
✓	Second meeting to discuss key considerations and threshold questions
✓	Develop draft outline of the DxF DSA
✓	Third meeting to introduce draft language for first set of topics <i>Topics: Privacy and Security; Technology Agnostic; Exchange Purposes; Requirement to Respond; Authorizations</i>
✓	Fourth meeting to introduce draft language for second set of topics <i>Topics: Authorizations, Special Compliance Provisions for HIPAA, Cooperation and Non-discrimination, Definitions</i>
3/22	Fifth meeting to introduce draft language for third set of topics and approach for P&P development <i>Topics: Uses and Disclosures, Minimum Necessary</i>
4/26	Sixth meeting to introduce proposed drafts for public comment of DxF DSA and initial set of P&Ps
5/18	Review draft DxF DSA and initial set of P&Ps at AG meeting
7/1	DxF DSA and P&Ps due

*The DSA Subcommittee provides input on DxF DSA development.

The DSA Subcommittee will not directly provide input on P&Ps but its discussions on the DxF DSA will inform P&P development.

DSA / P&Ps: Emerging Approach and Key Concepts

Overarching Structure

The DxF data sharing agreement will be a streamlined document designed for execution by a diverse set of mandated signatories. Accompanying policies and procedures documents will contain detailed guidance to support implementation.

DxF Data Sharing Agreement (DSA)

A legal agreement that a broad spectrum of health organizations execute by January 31, 2023

DxF DSA Components

- Streamlined document that focuses on the key legal requirements
- Avoids duplication or conflicts with other data sharing agreements

Example DxF DSA Content

Parties, purpose, intent, definitions, uses & disclosures, minimum necessary

DxF Policies and Procedures (P&Ps)

Rules and guidance to support “on the ground” implementation

DxF P&P Components

- Detailed implementation requirements
- Evolve and be refined over time through a participatory governance process involving stakeholders

Example DxF P&P Content

Technical standards and specifications, compliance and penalties, dispute resolution

DSA / P&Ps: Emerging Approach and Key Concepts

P&P Development Approach

A set of foundational policies and procedures (P&Ps) will be developed by July 1, 2022.
Additional P&Ps will continue to be developed and rolled out over time.

P&Ps to be Established by 7/1

Governance and Accountability

- ❖ Dispute Resolution
- ❖ Change Process for the P&Ps
- ❖ Change Process for the DSA

Technical Specifications

- ❖ Data Elements to Be Exchanged

Privacy and Security

- ❖ Breach Notification

Operations

- ❖ (Tentative) Requirement to Respond

Note: The list of P&Ps to be established by 7/1 included in this presentation will be discussed with the DSA Subcommittee at its March meeting and may be subject to change.

Data Exchange Framework Development Status Update

Digital Identities Strategy

Digital Identity Strategy: Requirements

AB133 requires that, by July 31, 2022, CalHHS in consultation with the Stakeholder Advisory Group, develop:

“a strategy for unique, secure digital identities capable of supporting master patient indices to be implemented by both private and public organizations in California.”

Digital ID: Focus Groups + Development Progress

Digital Identities Focus Groups

Purpose: CalHHS is convening focus groups across several stakeholder constituencies to gain input on a strategy for digital identities:

- Consumers
- Health Care Providers
- Health Plans
- HIEs
- Social Service Organizations
- State Health & Human Service Departments

Roles: Focus groups will provide perspective-specific input used in developing a strategy for digital identities. Input from and questions raised by focus groups will be shared with the AG.

Status	Digital Identities Strategy Development Step
Jan	Assess DxF participant needs; explore overarching approaches
Feb	Refine needs and explore strategy components
Mar	Refine strategy components with emphasis on privacy, security
Apr	Complete a draft strategy, discuss at the April AG meeting, solicit public comment
May	Refine strategy; align potential requirements with DxF, DSA
Jun/Jul	Finalize strategy for delivery to legislature

Two meetings of each focus group completed in Jan-Mar

One additional meeting of each focus group pending in Apr

Digital ID: Emerging Approach and Key Concepts

Unique, Secure Digital Identities

Digital Identity:	a collection of data that establishes an identity associated with a real person in a specific context, here with health and human services data exchanged via the DxF
Unique digital identity:	a digital identity that uniquely identifies an individual
Secure digital identity:	a digital identity that is protected against unauthorized access or modification, or intentional or unintentional loss or corruption

Do not create a new health identifier: Use existing data elements already assigned to an individual instead

Focus on linking health and human services data to the correct individual: Include only data elements that will aid in linking individuals to their data; do not strive for a “golden record” or force identity-proofing

Include data elements demonstrated to aid in a unique identity: Begin with elements from USCDI v1 useful for linking individuals to data, recognizing that demographics can only uniquely identify in aggregate; add elements beyond USCDI v1 that uniquely identify an individual

Ensure privacy: Not only protect against unauthorized access, modification, corruption, or loss, but also against inappropriate use or disclosure

Digital ID: Emerging Approach and Key Concepts

Supporting Master Person Indices

Master Person Index (MPI): Databases that identify and cross-reference persons across different organizations, systems, and contexts

Do not replace existing MPIs: Allow organizations participating in the DxF to continue to optimize their own systems to identify individuals

Consider an option that includes a statewide index

- Coordinates identities and data linking across organizations, systems, and contexts in the DxF
 - Helps ensure all organizations are identifying the same individual when linking and sharing data
 - Helps ensure security to protect individual privacy
- Draw on nationwide and statewide models and best practices that use a master person index

DxF Development Considerations and Next Steps

DxF Development Considerations

Key Themes



- **Funding:** Stakeholders have raised questions about the source of financial support for DxF/DSA implementation, including building necessary HIT capacity and providing technical assistance. CalHHS has emphasized the importance of aligning DxF/DSA implementation with existing state initiatives and identifying federal, private sector, and philanthropic resources that may be leveraged.



- **Alignment with Existing Data Sharing Initiatives:** Stakeholders have supported alignment between the provisions and data sharing agreements of the DxF and those of existing networks (e.g., TEFCA, Carequality, eHealthExchange). CalHHS continues to leverage existing provisions and agreements in the development of the DxF, aligning with national networks and reducing the potential for conflict or duplication of efforts.



- **Inclusion of Social Services Organizations:** Stakeholders have noted that social services organizations, while not mandated signatories of the DxF DSA, are meaningful participants in health data exchange and should be included within the scope of the DxF. CalHHS has stated that the DxF and its DSA will be designed to allow execution by mandated signatories while also lowering barriers to participation for social services organizations, to the extent possible.



- **Future Policy Guidance:** The DxF, DSA, and P&Ps are being quickly developed with the support of multiple stakeholder advisory groups. While we anticipate meeting legislatively required deadlines, additional policy guidance will likely be required beyond the July legislative deadline to clarify more complex and detailed issues.

Review and Finalization Process

Full drafts of the DxF, DSA, and P&Ps are being developed for discussion at the May AG meeting (May 18th). The digital identities strategy will be discussed earlier at the April AG meeting (April 7th). All deliverables will be released for public comment and iteratively revised based on stakeholder feedback.

DI Strategy	Review and Finalization Milestone	DxF / DSA / P&Ps
4/7	Full draft of deliverable discussed at AG meeting and released for public comment	5/18
4/21	Public comment period closes	6/1
Late April / Early May	Revise draft deliverable	Early June
May / June	State leadership review draft deliverable; revise draft deliverable	Mid June
6/23	Final draft of deliverable discussed at June AG Meeting	6/23
7/31	Finalize and publish deliverable	7/1

Next Steps and Milestones

Next Steps

- Continue development of the DxF, DSA, P&Ps, and digital identities strategy
- Share draft deliverables with the AG at the April and May meetings
- Release draft deliverables for public comment following AG discussion
- Revise draft deliverables and steward through rounds of state leadership review
- Share final draft deliverables at the June AG meeting

Milestones through Jul 2022

Meetings

- DSA Subcommittee Meeting #6, to discuss final set of topics and concepts for initial set of P&Ps
- Stakeholder Advisory Group Meetings #7 -9 to review draft and final versions of the DxF, DSA, P&Ps, and digital identities strategy

Deadlines

- Jul 1, 2022: Deliver DxF, DSA, P&Ps
- Jul 31, 2022: Deliver Digital ID Strategy

Appendix I.

Addressing Health Information Technology Capacity Gaps

Potential Opportunities

Addressing Health Information Technology Capacity Gaps

Gaps: Technical Infrastructure - HIT

- 1. EHR Adoption.** EHR adoption is limited among some health care organizations, particularly those without access to HITECH and other federal and state modernization funding opportunities (e.g., behavioral health, long term care facilities, correctional facility health providers); not all EHRs are certified or have capacity to share data using national standards.
- 2. Data Exchange Capacity at Many Health Care and Human Service Organizations.** Many human service organizations have limited technological capacity to store, electronically share, and use health and human service information.
- 3. Event Notifications.** Alerts and notifications today are mostly limited to transitions from acute care facilities and are not widespread for housing, incarceration status and other important events.
- 4. Intra- & Inter- Sector Data Exchange.** Some state, county, and other local government public health and human service organization information systems have limited capabilities to electronically exchange timely and usable health information with health care organizations.

Gaps and Opportunities

1. EHR Adoption

- **Opportunity 1:** Consider a Multi-Payer EHR Incentive Program

2. Data Exchange Capacity at Many Health Care and Human Service Organizations

- **Opportunity 2a:** Consider a HIE On-Boarding Program
- **Opportunity 2b:** Consider Qualifying Information Exchange Intermediary and Data Sharing Policies

3. Event Notifications

- **Opportunity 3a:** Consider Policies that Expands Event Notification Requirements

4. Intra- & Inter-Sector Data Exchange Capabilities

- **Opportunity 4a:** Consider Developing a Public Health and Human Services Data Exchange Capacity Building Program
- **Opportunity 4b:** Consider Policies that Expand Human Service Data Reporting Requirements

Gaps and Opportunities: EHR Adoption

Gap #1: EHR adoption is limited among some health care organizations, particularly those that did not have access to HITECH and other federal/state modernization funding (e.g., behavioral health, long term care facilities, correctional facility health, and small physical health providers); not all EHRs are certified or have capacity to exchange data using national standards.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the:*

- *Storage, maintenance, and management of health information. [§130290(c)(3)(B)(iii)]*
- *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Opportunities:

- A. Consider EHR Incentive Program:** Build on investments being made by the state to private payers to incentivize adoption of certified EHR technology (CEHRT) and, for non-HIPAA covered entities, qualifying clinical documentation technologies that support the collection, exchange, and use of electronic health information in accordance with state requirements.
- **Models:** U.S. HHS HITECH, NC [EHR Incentive Program for BH/IDD Providers](#), [NJ Substance Use Disorder Promoting Interoperability Program](#)
- B. Consider EHR Implementation Training & Technical Assistance:** Incentive programs can be coupled with technical assistance to support health care organizations adoption of EHRs.
- **Models:** HITECH [Regional Extension Centers](#), DHCS CA [Technical Assistance Program](#)
- C. Consider Promoting Certified EHR Requirements in State Programs:** [Certified](#) EHR technology requirements can be incorporated into state contracting (e.g., Covered California, DHCS managed care, CalPERS QHP contracts); may be particularly important for advancing integrated behavioral health (see MACPAC June 2021 [reporting](#)).
- **Models:** Medicare [Quality Payment Program](#) (QPP)

Opportunity #1: Multi-Payer EHR Incentive Program

(1a) Consider a Multi-Payer EHR Incentive Program that incentivizes health care organizations to adopt EHR technology capable of collecting, exchanging, and using electronic health information pursuant to AB-133. The scope of the incentive program would include health care organizations required by AB-133 to execute the Dx/F Data Sharing Agreement that were not previously eligible for HITECH funding, and who have a demonstrated financial need – including acute psychiatric hospitals and certain behavioral health providers.

Potential EHR incentive program funding could be directed towards adoption of CEHRT for HIPAA-covered entities, clinical documentation technologies that are not CEHRT could be supported for non-HIPAA covered entities, as long as those technologies are capable of and implemented to support California's Dx/F goals and objectives and DSA requirements.

Public and private payers may allow potential EHR incentive program funding to be used to upgrade providers' existing EHRs as long as in doing so, providers meet specified Dx/F goals and objectives and DSA requirements. Guidance should be developed to support provider selection of technology and services that meet state data sharing requirements.

The state is making significant investments over the next three years in this priority area, including through CalAIM, which will provide funding through the [Incentive Payment Program](#), [PATH](#) and the [Behavioral Health Quality Incentive Program](#) that support adoption of interoperable electronic health records and care management documentation systems. Additional resources and funding sources - particularly for small and solo-community providers, providers serving underserved populations and communities and behavioral health providers – should be investigated by public and private payers.

Public and private purchasers including Covered California, Medi-Cal, and CalPERS, and commercial health plans should establish value-based payment arrangements that align with these public requirements and advance use of CEHRT for HIPAA-covered entities and qualifying clinical documentation technologies that support information exchange. The program should be coupled with efforts to advance federal policy to provide funding to providers that were ineligible for incentive payments under the HITECH Act. It can be further reinforced through proposals leveraging the federal SUPPORT Act (P.L. 115-271) which authorized the Center for Medicare and Medicaid Innovation (CMMI) to test EHR incentive payments for behavioral health providers that contract with state Medicaid plans (*note: CMMI has yet to implement this demonstration*).

Gaps & Opportunities: Data Exchange Capacity at Many Health Care and Human Service Organizations

Gap #2: Many health care and human service organizations have limited technological capacity to store, electronically share, and use health and human service information.

Relevant AB 133 Provision(s): *Identify which data beyond health information as defined in paragraph (4) of subdivision (a), at a minimum, should be shared for specified purposes between the entities outlined in this subdivision and subdivision (f).*
[§130290(c)(3)(A)] Minimum “health information” sharing requirements in AB-133 are defined for specific health care organization, but broadly include provider sharing of USCDI and “electronic health information” per Section 171.102 of Title 45 of Code of Federal Regulations, and payer sharing of data per federal Interoperability regulations.

Opportunities:

- A. Consider a Health and Human Service Organization HIE Onboarding and Technical Assistance Program.** A program can be established to provide funding, incentives, and technical assistance to help health and human service organizations securely exchange electronic health information to support onboarding to a qualifying data exchange intermediary in accordance with AB 133, DxF priorities and state requirements.
- **Models:** CA DHCS [California HIE Onboarding Program \(Cal-HOP\)](#), [TNC Tailored Care Management Capacity Building Program](#)
- B. Consider a Data Sharing Intermediary and Data Sharing Requirements Policy.** Policy can be established that leverages national programs that define data sharing intermediary qualifications and further specify additional state data sharing requirements pursuant to AB-133 that should be incorporated into the DxF Data Sharing Agreement.

Opportunity #2: HIE On-Boarding Program, Qualified Networks and State Data Sharing Requirements

(2a) Consider an HIE Onboarding Program that provides incentives to health and human service organizations to participate in information exchange in accordance with AB-133, including supporting onboarding to qualified information exchange intermediaries. Potential HIE onboarding program funding should be used to support onboarding, not to defray ongoing costs associated with connecting to a qualifying information exchange intermediary. The state's commitment to support information exchange through the [Incentive Payment Program](#), [PATH](#), and the [Behavioral Health Quality Incentive Program](#) should be coupled with private sector investments that support HIE onboarding.

The program should include establishing a technical assistance "Center of Excellence" to provide support for implementation, potentially through a statewide program funded by philanthropic investments and/or private and public payers.

Lessons learned from other HIE Onboarding Programs (e.g., Cal-HOP) should be explored to identify participation and technical barriers and lessons learned, with a focus on behavioral health agencies (e.g., identifying challenges navigating data sharing consent related to 42 CFR Part 2), and other under-resourced providers, small provider organizations and practices.

(2b) Consider Qualifying Information Exchange Intermediary and Data Sharing Policies that adopt national programs that qualify health information networks (i.e., Sequoia Project Regional Coordinating Entity and TEFCA), and specify additional California DxF requirements that Qualified Intermediaries must meet to participate in state-sponsored data sharing programs. The state's qualification processes, requirements and criteria should be established and overseen by data exchange governance processes supported by the state. State policies would further specify how federal data exchange requirements (CMS-9115-F, 85 FR 25510) and additional state-specified data sharing requirements and use cases should be incorporated into the DxF Data Sharing Agreement.

Gaps and Opportunities: Event Notifications

Gap #3: Event notifications today are mostly limited to transitions from acute care facilities and are not widespread for housing, incarceration status and other important events.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in:*

- *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Opportunities:

- A. Consider Expanding Federal Alert Notification Requirements:** State policy and contracting requirements can be developed, extending the scope and scale of federal Interoperability and Patient Access Final Rule ([CMS-9115-F](#)) notification requirements to additional health and human service organizations.
- **Models:** FL Medicaid managed care plan [contracts](#) with required linkages to pre-booking sites for behavioral health assessments and potential diversion; AZ Medicaid managed care plan/justice system data [connections](#) and Medicaid requirements to support transitions; MI Medicaid [pilot](#) to identify homeless individuals by HMIS matching; CA WPC Pilot program [lessons learned](#)

Opportunity #3: Expand California Alert Notification Requirements

(3a) Consider Policies that Expand Event Notification Requirements, specifying how the DxF Data Sharing Agreement should build on federal data exchange requirements (CMS-9115-F, 85 FR 25510) to expand the scope of event notification requirements in California and envisioned by AB-133. Policies may:

- Expand event notification requirements described in [CMS-9115-F](#) to:
 - Require notifications to be sent to a beneficiary's health plan/payer; and,
 - Establish a goal to expand alert notification requirements to additional entities (e.g., housing agencies, jails, youth correctional facilities, state prisons and state hospitals) to alert care team members to changes in a client's incarceration, housing and other statuses.
- Establish state licensing requirements for entities required to provide event notifications.
- Establish contracting requirements for entities required to provide event notifications through public and privately financed coverage programs.
- Provide additional guidelines for event notification requirements from incarceration settings (jails, youth correctional facilities and state prisons) to ensure timely notifications related to individuals with physical and behavioral health needs that include the type of information useful to managing care transitions, and to ensure that the appropriate Releases of Information (ROIs) are provided to physical, behavioral, social service and other care team members where appropriate.

Gaps & Opportunities: Intra- & Inter-Sector Data Exchange Capabilities

Gap #4: Some state, county and other local government public health and human service organization information systems have limited capabilities to electronically exchange timely and usable health information with health care organizations.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in...Linking, sharing, exchanging, and providing access to health information.[§130290(c)(3)(B)(iv)]*

[By] January 31, 2023, [CalHHS] shall work with the [CA] State Association of Counties to encourage the inclusion of county health, public health, and social services, to the extent possible, as part of the [DxF] in order to assist both public and private entities to connect through uniform standards and policies. It is the intent of the Legislature that all state and local public health agencies will exchange electronic health information in real time with participating health care entities... [§130290(c)(5)(E)]

Opportunities:

- A. Consider Upgrades to California County Health IT Infrastructure:** Leverage and expand federally funded programs to upgrade state and local public health IT infrastructure and to provide a glidepath for county health, public health, and social service entities to participate in information exchange.
- **Models:** CDC [Data Modernization Initiative](#) nationally and CA's ~\$300m allocation for public health modernization
- B. Consider Developing Public Agency Data Exchange Policy and Contracting Requirements.** Through policy (e.g., statewide HMIS reporting to centralized Homeless Data Integration System [[HDIS](#)] via [AB977](#)), procurement processes and contract amendments, public agencies could contractually obligate vendors to share information with health and human service organizations to advance goals envisioned by AB-133.
- **Models:** Merced and San Joaquin County [contracts](#) with EHR vendors serving their county jails

Opportunity #4: **Public Data Exchange Capacity Building Program**

(4a) Consider Developing a Public Health and Human Services Data Exchange Capacity Building Program that leverages and aligns with federally-funded modernization efforts to support local health, public health, justice-involved, housing, and social service organization data exchange capacity to advance priority health data exchange use cases envisioned by AB-133 and outlined by the DxF. The program would seek funding from federal sources to support upgrades to technology that can support data sharing with stakeholder groups referenced in AB-133.

(4b) Consider Policies that Expands Human Service Data Reporting Requirements. Establish policies requiring public funded programs to incorporate data sharing requirements into procurements and vendor contracts. Policies would apply to use cases defined pursuant to the DxF and include flow-down requirements for vendor contracting (e.g., HMIS vendors, prison/jail EHR vendors).

Appendix II.

Data Exchange Standards, Provider Identity Management, and Consumer Data Access

Potential Opportunities:
**Data Exchange Standards, Provider
Identity Management, and Consumer
Data Access**

Gaps: Standards and Consumer Access

- 1. Human Service Data Exchange Standards and Capacity.** National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of SDOH and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.
- 2. Demographic Data.** Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared, and multiple standardized terminologies exist and regulations conflict on which must be supported.
- 3. Provider Identity Management.** Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.
- 4. Consumer Data Access.** Individuals consistently face challenges in accessing and contributing to their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

(Covered by Digital Identity Strategy) Person Identity Management. Robust person identity matching services are not available or accessible to health and human service organizations across California.

Gaps and Opportunities

- 1. Human Service and Demographic Data Exchange Standards and Capacity***
 - **Opportunity 1a:** SDOH data collection and use standards, requirements, and incentives
 - **Opportunity 1b:** Demographic data collection and use standards, requirements, and incentives
 - **Opportunity 1c:** Enhance cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care
 - **Opportunity 1d:** Advance recommendations to federal government to improve demographic data collection nationally
- 2. Provider Identity Management****
 - **Opportunity 2a:** Expand upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule.
 - **Opportunity 2b:** Require qualifying HIOs to participate in a federated provider identity management service
- 3. Consumer Data Access**
 - **Opportunity 3a:** Adopt policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions
 - **Opportunity 3b:** Adopt policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use

*Combines two previously identified gaps for solutioning purposes

**Previously identified "Person Identity Management" is being addressed through the Digital Identity Strategy process

Gap #1: Human Service and Demographic Data Exchange Standards and Capacity (1 of 2)

Gap #1a: National and federally recognized human service data exchange standards are nascent, and the standardized collection, exchange, and use of Social Determinants of Health (SDOH) and other human service information remains limited; national networks, HIOs, and EHRs generally have limited capabilities to exchange structured and standardized SDOH and other human service data.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to social determinants of health, such as housing and food insecurity, into shared health information. [§130290(c)(3)(C)]*

Key Considerations:

- SDOH data collection efforts remain largely nascent, though are developing to allow health care organizations to better understand and support individuals' whole person care needs. SDOH – the conditions in the environments where people are born, live, learn, work, play, worship, and age – are estimated to account for up to 80% of health outcomes; understanding and addressing these factors is central to improving the health and wellbeing of all Californians. DHCS' CalAIM program focuses on addressing SDOH ([link](#)).
- SDOH data may be collected:
 - **Directly** from interactions with an individual (e.g., patient screening, observed conditions noted in clinical records or on claims).
 - **Indirectly** from changes in an individual's engagement with the human service system (e.g., SNAP enrollment/food insecurity, HMIS identification/housing insecurity, jail and prison data to support care transitions).
- SDOH data **directly** collected from interactions with an individual and recorded in:
 - Screenings or in clinical records that are often not collected in alignment with federal standards and definitions, such as the USCDI v2 (released by ONC in July 2021 and available [here](#)), as health care organizations sought to collect information prior to federal or national standards being widely disseminated.
 - Claims/encounters using the ICD-10-CM codes (primarily Z55-65 under *Factors influencing health status and contact with health services*, described [here](#)) remain limited ([link](#)), as health care organizations frequently do not have financial incentives or training to accelerate use.
- SDOH data that may be **indirectly** collected from changes in an individual's engagement with human service programs may not always be accessible in a timely manner to health care organizations that could use it to inform an individual's care and/or connect individuals with needed supports due to various legal, operational, and technical barriers to data exchange.

Gap #1: Human Service and Demographic Data Exchange Standards and Capacity (2 of 2)

Gap #1b: Race, ethnicity, languages (spoken/written), sexual orientation, gender identity and other demographic data necessary to support population health and to identify and address disparities and inequities are often missing, incomplete, or are not collected or shared.

Relevant AB 133 Provision(s): *Identify ways to incorporate data related to underserved or underrepresented populations, including, but not limited to, data regarding sexual orientation and gender identity and racial and ethnic minorities.*
[§130290(c)(3)(D)]

Key Considerations:

- Demographic data collection completeness and consistency across health and human service programs varies significantly by data type.
 - “Gender” data are almost universally collected against a consistent – though outdated – male/female classification schema.
 - “Sexual Orientation” and “Gender Identity” data are rarely collected at present, and when collected, are captured against varying local or industry standards.
 - “Race”, “Ethnicity”, and “Language” (preferred spoken/written) data are almost universally voluntarily solicited by programs from individuals, but frequently left blank, and collected against varying federal, state, local, and industry standards.
 - Current inadequacies in data elements can have serious implications for clinical decision support, quality of care, and health disparities.
- Health disparities in California are pervasive, and reflective of structural racism in our society and inequities in our systems of health. For example, Black Californians are expected to live 11 years less than Asian Californians, and experience the highest death rates from breast, cervical, colorectal, lung, and prostate cancer among all racial and ethnic groups ([CHCF Brief](#)); while nationally – according to [data from the Trevor Project](#) – 42% of LGBTQ youth seriously considered attempting suicide in 2021. Understanding Californians’ unique diversity and the barriers specific groups may face in accessing and receiving health care is essential for ensuring their long-term health and wellbeing.
- Demographic data are ideally collected directly from an individual against standardized definitions. However, many individuals are hesitant to volunteer such information for fear of discrimination. Health care organizations may “fill in” missing demographic data with “indirect” data matched from other data sources or through statistical imputation (i.e., approximations based on other individual information). There are no systemic operational/technical methods in the health care ecosystem to maintain a “[hierarchy of truth](#)” (i.e., member data vs. indirect data).
- Demographic data collection, curation, and use will benefit from data standards, protocols, and practices that may not presently be in place across the health care data ecosystem – or nascent in implementation. For example, the [Gravity Project](#) is working to incorporate both source and method of collecting certain demographic data alongside the value itself. In addition, federal HRSA and UCSDI demographic data standards conflict and may cause confusion in the market.

Opportunity #1: Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities (1 of 4)

(1a): Consider establishing SDOH data collection and use standards, requirements, and incentives. CalHHS should adopt the US Core Data for Interoperability (USCDI) Version 2 standards to facilitate consumer SDOH data collection, in addition to consumer race, ethnicity, language, sexual orientation, gender identity, social and behavioral risk information (see Opportunity #2a). Standards may be paired with common data collection, data quality and performance reporting requirements and incentives through public and private payers to support system change. Data collectors and users may also require technical assistance to support new data collection and use practices.

California DHCS has prioritized identifying and addressing SDOH through [CalAIM](#), which builds upon its Whole Person Care (WPC) pilot program that promoted coordinated care – physical, behavioral, and social – for high-risk, high-utilizing Medi-Cal enrollees by increasing service integration and SDOH data sharing and use among counties, plans, and CBOs. Successful WPC pilots – including [Alameda County Care Connect](#), [LA County WPC](#), [Marin County WPC](#), and [San Francisco DPH WPC](#) – each established new data sharing protocols to support the exchange of SDOH related information. More broadly, CMS has [encouraged](#) state Medicaid and CHIP programs to adopt strategies that address SDOH, including instituting new data collection and reporting requirements, investing in systems capable of exchanging SDOH data, and programs that can put such data to meaningful use. Many states already incorporate SDOH screening and/or referral requirements in their Medicaid MCO contracts; and use quality reporting requirements and incentive payments to monitor and reward SDOH progress ([KFF overview](#)).

Opportunity #1: Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities (2 of 4)

(1b): Consider establishing demographic data collection and use standards, requirements, and incentives. Paired with Opportunity #1a, California may work with private health care organizations to establish and require demographic data collection and reporting (e.g., race, ethnicity, sexual orientation, gender identity, disability status, etc.) in accordance with federal standards (e.g., CDC and OMB, USCDI v2.0), and ensure consistent and comprehensive demographic data collection across public and private entities (e.g., [Connecticut SB-1](#)). As indicated in Opportunity (1a), California should also have a process to evaluate relevant new federal standards as they are released in order to determine how they may be implemented. Standards may be paired with common collection and reporting requirements (e.g., MCP/provider quality/performance reporting) and incentives through public (e.g., Medi-Cal, CalPERs, and Covered California) and private payers to use data to identify and reduce disparities. Data collectors/users may require technical assistance to support new data collection and use practices.

DHCS [analyzes](#) Medi-Cal MCP quality data through its External Quality Review Organization (EQRO) process to assess potential differences in health outcomes between racial and ethnic population groups and shares those analyses with MCPs to guide interventions. DHCS also emphasizes increased data collection to reduce disparities and inequities through [CalAIM](#). Covered California, meanwhile, continues to increase its race and ethnicity data reporting and use [expectations](#) for its QHPs. CDPH has also collected demographic and SDOH data to inform the state's response to COVID-19. More broadly, CMS has prioritized its expansion of the "collection, reporting and analysis of standardized data" – including race, ethnicity, language, sexual orientation, gender identity, and disability status - in its Medicare [Equity Plan](#), as broader federal action in this area has been [encouraged](#).

Opportunity #1: Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities (3 of 4)

(1c): Consider enhancing cross-state agency data sharing efforts to support the exchange of program enrollment data and consumer demographic and SDOH information to support cross-program service coordination and whole person care.

California may enhance its interagency data sharing efforts in accordance with the Framework’s vision and goals to allow – in compliance with federal law – the sharing of individuals’ public program information across agencies and departments, and with health and human service organizations and consumers, to support coordinated service delivery and improve the health and wellbeing of Californians. Data sharing may include program enrollment, demographic, service utilization, and/or health and human service needs information captured by agencies and departments including:

- DHCS/Medi-Cal, including enrollment and identified social needs (if captured on claims/encounters);
- DPSS/[CalFresh](#), including enrollment and other food insecurity indicators;
- BCSH/Homeless Data Integration System ([HDIS](#)), including enrollment and other housing stability indicators;
- DOJ/Criminal Justice Statistics Center ([CJSC](#)), including justice involvement and probation events or transitions;
- DSS/Child Welfare Services/Case Management System ([CWS/CMS](#)), including intake, screening, and health/social needs data; and
- Covered CA and CalPERS, including enrollment and identified social needs (if captured on enrollment, screenings, and claims/encounters).

California may evaluate the feasibility and efficacy of incentivizing the connection to and expansion of health information exchanges, community information exchanges (CIEs), and other intermediaries to support cross-program and cross-sector exchange and use of SDOH and demographic data.

Under CalAIM, health care organizations will be expected to identify SDOH needs directly from individuals, if not available directly through state systems or regional CIEs, such as San Diego CIE and Access Sonoma (see [case examples](#)).

DHCS could potentially leverage enhanced federal Medicaid matching funds for “state expenditures to design, develop, install, or enhance” interoperable systems capable of identifying individuals’ SDOH needs and sharing that information with appropriate medical and social support services ([CMS guidance](#)).

Opportunity #1: Improving SDOH and Demographic Data Collection and Use to Identify and Address Health Disparities (4 of 4)

(1d): Consider advancing recommendations to federal government to improve demographic data collection nationally.

Race and ethnicity data collection remain uneven across the health care data ecosystem, with applications limited for its use. And multiple federal standards also exist; HRSA for example does not align with USCDI v1 or v2. As such providers in HRSA(e.g., FQHCs) programs must now support both standards. Sexual orientation and gender identity data collection are also relative nascent, with federal standards only now emerging. Demographic data should accurately reflect the truth of the individual, though the technical systems and protocols for collection that presently exist do not always reflect this value – or collect/maintain needed meta information required to preserve that testimony (i.e., systems do not identify whether demographic information was provided directly by the member or collected through other sources).

As California advances a Data Exchange Framework that prioritizes health equity, it should develop processes to identify both ***misalignment*** of national standards and ***gaps*** in our national data collection, curation, and use standards, including standards promulgated by HRSA, CMS, ONC, OCR, SAMHSA and other federal agencies that design and implemented new national standards. California should develop a process to advocate for and advance data standard that better align national standards and fill data standard gaps that are needed to advance state priorities. And California should develop processes to evaluate relevant new proposed federal SDOH standards and data collection, sharing and use regulations to determine whether and how they may be implemented and improved. For example, California could evaluate emerging draft USCDI Version 3 standards that support more consistent functional, cognitive and other disability status data collection, sharing, and use, and provide recommendations to the federal government to improve those standards before they are adopted.

Gap #2: Provider Identity Management

Gap #2: Robust provider, care team, and social service organization directories are not available or accessible to health and human service organizations across California.

Relevant AB 133 Provision(s): *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the: Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*

Key Considerations:

- Provider identity management can be improved to support various objectives, including, but not limited to understanding bidirectional:
 - **Individual-to-provider** relationships (i.e., attribution) to support care coordination;
 - **Provider-to-provider** data exchange addresses to ensure the appropriate and secure routing of individual information; and
 - **Provider-to-plan** data exchange (i.e., provider directories) to ensure plans maintain up-to-date network information to share with their members.
- California has invested significant public and private resources into improving **provider-to-plan** data exchange through [Integrated Healthcare Association in California's Symphony project](#).
 - Other national provider directories include [DirectTrust](#) and [the National Plan & Provider Enumeration System \(NPPES\)](#) (National Provider Standard).
 - [CMS's recent Interoperability and Patient Access Final Rule](#) and California's [SB-137](#) stipulate more rigorous requirements for certain plans to maintain up-to-date consumer-facing provider directories.
- While provider-to-provider address directories may be tied to provider directories, less progress has generally been made in ensuring their timeliness and reliability.
- Several challenges exist to developing robust provider identity management systems, including:
 - Many widely used identifiers have shortcomings for advancing the objectives above. For example, many billing providers have an NPI, but not all treating providers do. Further, both organizations and individual providers can have NPIs, potentially causing confusion.
 - Provider clinical, system affiliation, and technical/address information can often change, requiring updates to the systems of all organizations that depend upon it.
 - Provider identity management systems are most effective when they can be used across organizations and sectors; however, this requires transparent governance.
 - Social service providers often lack robust identity management processes that are compatible with identifiers and processes used in the health care sector. Some private sector organizations (such as kno2) offer solutions that facilitate data sharing between health and social service providers.

Opportunity #2: Enhance Provider Directory Requirements to Incorporate Provider Address Information (1 of 2)

(2a): Consider expanding upon the provider directory API Requirements in CMS's Interoperability and Patient Access Final Rule. California could require all signatories of the DxF DSA to maintain and update identity credentials. The requirement in CMS's Interoperability and Patient Access Final Rule ([CMS-9115-F](#)) that specified payers offer a public facing Provider Directory API using a FHIR-based API, specifically, the PDEX Payer Network Implementation Guide, could be expanded to include:

- All payers licensed in California, including Qualified Health Plans (QHPs); and
- DxF DSA signatories, such that all parties provide updated credentials to payers and to any qualifying health information exchange intermediaries with which they share data.

California could also consider building upon [SB-137](#) to require the posting of NPI type 1 (organizational) and type 2 (individual provider) information to include other information including provider Endpoints.¹

¹ *Endpoints provide a simple, secure, scalable, and standards-based way for participants to send authenticated, encrypted health information directly to known, trusted recipients over the Internet. In NPPES, providers can enter Endpoint information when they request new NPIs or when they update their NPI information. The Endpoint details can be entered on both Individual (Type 1) and Organization (Type 2) NPI applications. This information will be made available on NPI Registry, APIs, and Data Dissemination Files for users to receive and consume.*

Opportunity #2: Enhance Provider Directory Requirements to Incorporate Provider Address Information (2 of 2)

(2b): Consider requiring qualifying HIOs to participate in a federated provider identity management service. There is significant value in implementing identity and master data management as a shared service to reduce individual organizational burden. The DxF can establish a set of requirements for qualifying HIOs that they deploy master data management approaches to identity management that include technical systems, processes, governance, policies, and standards to establish a consistent reference identity for individuals, the data attributed to them, the identity of providers, provider membership in organizations, and patients attributed to them. ([ONC's State Health IT Modular Functions for Value-based Payment Strategic Implementation Guide](#))

Gap #3: Consumer Data Access

Gap #3: Individuals consistently face challenges in accessing their health and human service records - directly or through selected third parties - in a manner that is convenient, timely and compliant with federal access requirements.

Relevant AB 133 Provision(s):

- *Identify gaps, and propose solutions to gaps, in the life cycle of health information, incl. gaps in the:*
 - *Linking, sharing, exchanging, and providing access to health information. [§130290(c)(3)(B)(iv)]*
- *Identify how all payers will be required to provide enrollees with electronic access to their health information, consistent with rules applicable to federal payer programs. [§130290(c)(3)(I)]*

Key Considerations:

- **Consumer Data Access and HIPAA.** Under, [HIPAA](#), patients have a legal, enforceable right to access their health records maintained by a covered entity such as a provider or health plan. In reality, numerous barriers exist to accessing one's own health data including complex access requirements, consumer portals that are difficult to navigate, fragmented data, financial costs (e.g., printing fees), and often health care organization non-compliance. The Health Information Technology for Economic and Clinical Health Act (HITECH) of 2009 also requires that HIPAA-covered entities (physicians, payers, clearinghouses, and their business associates) who use EHRs must follow a direction from a patient to transmit the patient's PHI electronically to any person, entity, or application the patient chooses, such as a public health agency, a community-based service provider, and the patient's third-party health application.
- **Recent Regulations and Frameworks.** [ONC's Cures Act Final Rule](#) includes provisions that support consumer data access, including efforts to curtail information blocking. [CMS's Interoperability and Patient Access Final Rule](#) requires CMS-regulated payers to make patient data, including claims and encounter data, available to patients via a secure, standards-based API. [TEFCA](#) counts easy access to electronic health information for individuals and their authorized caregivers as one of its principles for trusted exchange.
- **Potential Opportunities.** Improving consumer data access will require an industry-wide effort with participation from both the public and private sectors.

Opportunity #3: Ensure Consumer Access to their Health Information (1 of 2)

(3a): Consider adopting policies to ensure consumers have meaningful access to their longitudinal health information across all health care organizations subject to AB-133, allowing them to make informed health care decisions. Potential policies and requirements to advance this objective may include:

- Expand federal information blocking and patient access API rules to all health care organizations subject to the DxF including:
 - All California licensed health plans and health care organizations listed in AB 133 subdivision (f)(1-6).
 - Requiring all health care organizations listed in AB 133 subdivision (f)(1-6) to implement and maintain a secure, standards-based ([HL7 FHIR Release 4.0.1](#)) API that allows patients to easily access their health information through third-party applications of their choice and made available electronically by the request of the individual.
- Evaluate where California law governs consumers access to their longitudinal health information (e.g., [California Health and Safety Code 123110](#)) since the federal Information Blocking and Patient Access Interoperability rules defer to state law.
- Provide consumers with bi-directional access to their health information maintained by health care organizations – including to add self-reported health information and correct inaccurate information to the extent allowed by law – in a manner that accommodates their preferred language, readability, disability access, and support access for those Californians who have limited access to technology or broadband and consider consumer health and IT literacy.
- Consumers should be provided with education and support by health care organizations on how to: access their health information; use their health information to inform their decision-making; and update their health information if inaccurate.

Opportunity #3: Ensure Consumer Access to their Health Information (2 of 2)

(3b): Consider adopting policies to ensure consumers understand how their health information may be used and trust in the systems in place that govern its use. Potential policies and requirements to advance this objective may include:

- California should review its current Fair Information Practices, consider updates and develop stronger guidelines that can be linked with the state's Data Sharing Agreement and future State Policy Guidance. Guidelines may include transparency about data policies; limitations on health information collection, use, and disclosure; consent; data quality, integrity, and security protections; and ensuring accountability through appropriate audit trails and enforcement. Guidelines should be clear to consumers around how their health information will be shared and where they have the ability to provide consent or not prior for its exchange and use, in alignment with state and federal laws
- California should develop practices and policies to hold DSA participants accountable for participation in the appropriate exchange and use of consumer health information, including:
 - Monitoring and evaluating participation and adherence to policies regarding data sharing, safeguarding and use of health information;
 - Integrate explicit protections against misuse of health data;
 - Supporting health care organization training on consumer access to health information; and
 - Supporting consumer feedback mechanisms to improve data access.
- The U.S. HHS Office of Civil Rights' [Individuals' Right under HIPAA to Access their Health Information 45 CFR § 164](#) and ONC's [2018 Model Privacy Notice](#) provide examples of clear guidance to inform consumers about data access and privacy policies.