

Data Exchange Framework Stakeholder Advisory Group Meeting #7

California Health & Human Services Agency

Thursday, April 7, 2022
10:00 a.m. to 12:30 pm

Meeting Participation Options

Onsite

- Members who are onsite are encouraged to log in through their panelist link on Zoom.
 - Members are asked to **keep their laptop's video, microphone, and audio off** for the duration of the meeting.
 - The room's cameras and microphones will broadcast the video and audio for the meeting.
- Instructions for connecting to the conference room's Wi-Fi are posted in the room.
- Please email (khousa.vang@chhs.ca.gov) Khousa Vang with any technical or logistical questions about onsite meeting participation

Meeting Participation Options

Written Comments

- Participants may submit comments and questions through the **Zoom Q&A box**; all comments will be recorded and reviewed by Advisory Group staff.
- Participants may also submit comments and questions – as well as requests to receive Data Exchange Framework updates – to CDII@chhs.ca.gov.

Meeting Participation Options

Spoken Comments

- *Participants and Advisory Group Members* must “raise their hand” for Zoom facilitators to unmute them to share comments; the Chair will notify participants/Members of appropriate time to volunteer feedback.

If you are onsite and not using Zoom

Physically raise your hand, and the chair will recognize you when it is your turn to speak

If you logged on onsite via Zoom interface

Press “Raise Hand” in the “Reactions” button on the screen or physically raise your hand

If selected to share your comment, please begin speaking and do not unmute your laptop. The room’s microphones will broadcast audio

If you logged on from offsite via Zoom interface

Press “Raise Hand” in the “Reactions” button on the screen

If selected to share your comment, you will receive a request to “unmute;” please ensure you accept before speaking

If you logged on via phone-only

Press “*9” on your phone to “raise your hand”

Listen for your phone number to be called by moderator

If selected to share your comment, please ensure you are “unmuted” on your phone by pressing “*6”

Public Comment Opportunities

- Public comment will be taken during the meeting at designated times.
- Public comment will be limited to the total amount of time allocated for public comment on particular issues.
- The Chair will call on individuals in the order in which their hands were raised, beginning with those in the room and followed by those dialed in or connected remotely through Zoom.
- Individuals will be recognized for up to two minutes and are asked to state their name and organizational affiliation at the top of their statements.
- Participants are encouraged to use the comment box to ensure all feedback is captured or email their comments to CDII@chhs.ca.gov.

Agenda

10:00 AM	Welcome and Roll Call <ul style="list-style-type: none">• <i>John Ohanian, Chief Data Officer, California Health and Human Services</i>
10:05 AM	Vision and Meeting Objectives <ul style="list-style-type: none">• <i>Dr. Mark Ghaly, Secretary, California Health and Human Services</i>
10:15 AM	Potential DxF Governance Model <ul style="list-style-type: none">• <i>Jonah Frohlich, Senior Managing Director, Manatt Health Strategies</i>
10:45 AM	Regulatory and Policy Opportunities <ul style="list-style-type: none">• <i>Jonah Frohlich</i>
11:15 AM	<u>Public Comment</u>
11:30 AM	Digital Identity Strategy Update <ul style="list-style-type: none">• <i>Dr. Rim Cothren, Independent HIE Consultant to CDII</i>
12:10 PM	Data Sharing Agreement Subcommittee Update <ul style="list-style-type: none">• <i>John Ohanian</i>
12:25 PM	Closing Remarks <ul style="list-style-type: none">• <i>John Ohanian</i>

Welcome and Roll Call

Advisory Group Members

Stakeholder Organizations (1 of 3)

Name	Title	Organization
Mark Ghaly (Chair)	Secretary	California Health and Human Services Agency
Jamie Almanza	CEO	Bay Area Community Services
Charles Bacchi	President and CEO	California Association of Health Plans
Andrew Bindman <i>designated by Greg A. Adams</i>	Executive Vice President; Chief Medical Officer	Kaiser Permanente
Michelle Doty Cabrera	Executive Director	County Behavioral Health Directors Association of California
Carmela Coyle	President and CEO	California Hospital Association
Rahul Dhawan <i>designated by Don Crane</i>	Associate Medical Director	MedPoint Management (representing America's Physician Groups)
Joe Diaz <i>designated by Craig Cornett</i>	Senior Policy Director and Regional Director	California Association of Health Facilities
David Ford <i>designated by Dustin Corcoran</i>	Vice President, Health Information Technology	California Medical Association
Liz Gibboney	CEO	Partnership HealthPlan of California

Note: Complete bios for each member are available in a publicly posted biography listing; updated on Sept. 30th at 5pm PT

Advisory Group Members

Stakeholder Organizations (2 of 3)

Name	Title	Organization
Michelle Gibbons <i>designated by Colleen Chawla</i>	Executive Director	County Health Executives Association of California
Lori Hack	Interim Executive Director	California Association of Health Information Exchanges
Matt Legé <i>delegate for Tia Orr</i>	Government Relations Advocate	Service Employees International Union California
Sandra Hernández	President and CEO	California Health Care Foundation
Cameron Kaiser <i>designated by Karen Relucio</i>	Deputy Public Health Officer	County of San Diego (representing the California Conference of Local Health Officers)
Andrew Kiefer <i>designated by Paul Markovich</i>	Vice President, State Government Affairs	Blue Shield of California
Linnea Koopmans	CEO	Local Health Plans of California
David Lindeman	Director, CITRIS Health	UC Center for Information Technology Research in the Interest of Society
Amanda McAllister-Wallner <i>designated by Anthony E. Wright</i>	Deputy Director	Health Access California

Advisory Group Members

Stakeholder Organizations (3 of 3)

Name	Title	Organization
DeeAnne McCallin <i>designated by Robert Beaudry</i>	Director of Health Information Technology	California Primary Care Association
Ali Modaressi	CEO	Los Angeles Network for Enhanced Services
Erica Murray	President and CEO	California Association of Public Hospitals & Health Systems
Janice O'Malley <i>designated by Art Pulaski</i>	Legislative Advocate	California Labor Federation
Mark Savage	Managing Director, Digital Health Strategy and Policy	Savage & Savage LLC
Kiran Savage-Sangwan	Executive Director	California Pan-Ethnic Health Network
Cathy Senderling-McDonald	Executive Director	County Welfare Directors Association
Claudia Williams	CEO	Manifest MedEx
William York	President and CEO	San Diego Community Information Exchange

Advisory Group Members

State Departments (1 of 2)

Name	Title	Organization
Ashrith Amarnath	Medical Director	California Health Benefit Exchange
Jim Switzgable <i>designated by Nancy Bargmann</i>	Deputy Director	Department of Developmental Services
Mark Beckley	Chief Deputy Director	Department of Aging
Scott Christman	Chief Deputy Director	Department of Health Care Access and Information
David Cowling	Chief, Center for Information	California Public Employees' Retirement System
Kayte Fisher	Attorney	Department of Insurance
Brent Houser	Chief Deputy Director, Operations	Department of State Hospitals
Julie Lo	Executive Officer	Business, Consumer Services & Housing Agency

Advisory Group Members

State Departments (2 of 2)

Name	Title	Organization
Dana E. Moore	Acting Deputy Director	Department of Public Health
Nathan Nau	Deputy Director, Office of Plan Monitoring	Department of Managed Health Care
Linette Scott	Chief Data Officer	Department of Health Care Services
Cheryl Larson <i>Designated by Diana Toche</i>	Director & CIO	Department of Corrections and Rehabilitation
Julianna Vignalats	Assistant Deputy Director	Department of Social Services
Leslie Witten-Rood	Chief, Office of Health Information Exchange	Emergency Medical Services Authority

Vision & Meeting Objectives

Vision for Data Exchange in CA

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.

AB-133's Call for Action

AB-133 describes why action is needed to advance data exchange.

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

Why is Governance Needed? What Should Governance Do?

Gap: California currently lacks a single governing body to develop, implement, and oversee policies that will advance the meaningful exchange and use of health and human services data throughout the state.

Relevant AB 133 Provision(s): *Assess governance structures to help guide policy decisions and general oversight.*
[§130290(c)(3)(J)]

Key Considerations:

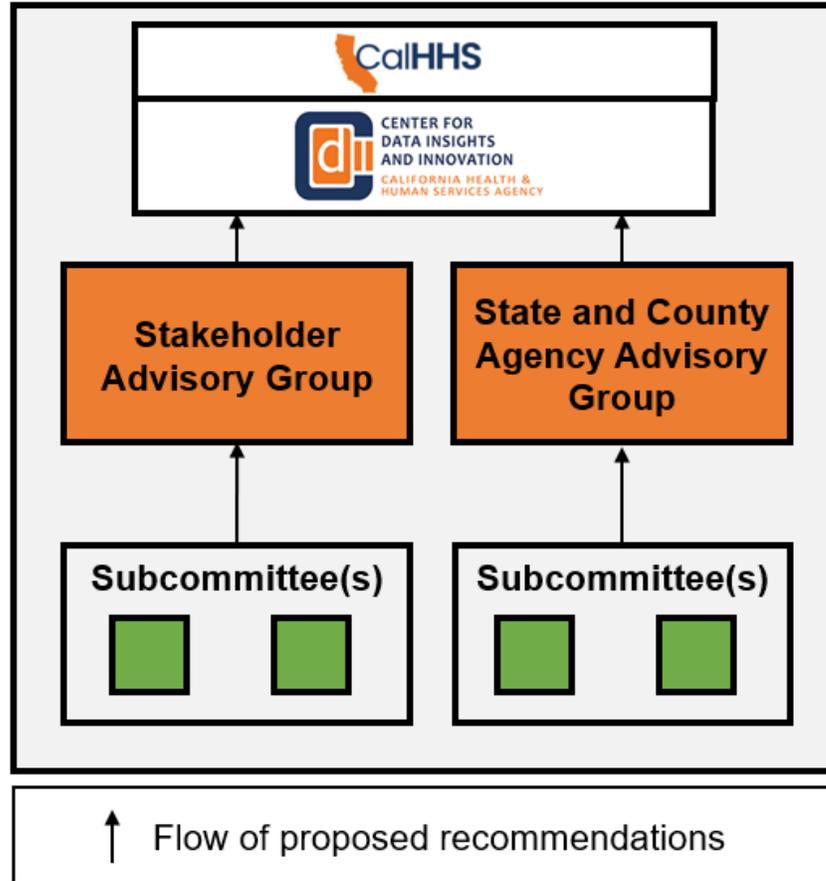
Health and human service data exchange and use is governed by an array of state and local government agencies and departments as well as other public and private stakeholders. The governance approaches and policies of these many actors may align in some instances but can also be conflicting.

Research has shown that states with successful health and human service data exchange governance models have the following characteristics:¹⁻³

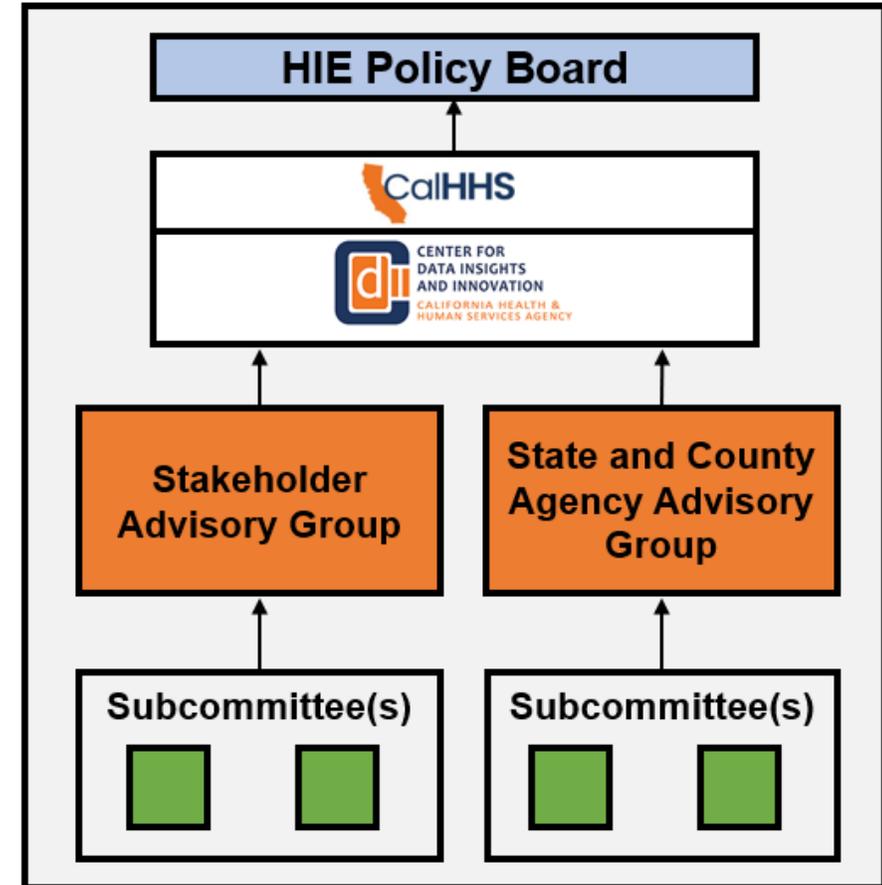
- **The State Takes a Strong Leadership Role:** States that have been most successful typically have a high-level official in a health and human services agency who can use rulemaking authority and access federal funding to advance the statewide health and human service data exchange.^{1,2}
- **Multi-Stakeholder Committees Provide Transparency and Accountability:** Successful states have multi-stakeholder committee(s) to help provide oversight, set priorities, and craft policies for statewide health and human service data exchange.¹

Governance Model Recommendation

July 1, 2022: Launch the DXF Framework with CDII managing & overseeing all aspects of Governance¹



January 2023: Establish HIE Policy Board with oversight role & CDII administrator role¹



1. Details on all governance structure options provided on the following slides.

Meeting #7 Objectives

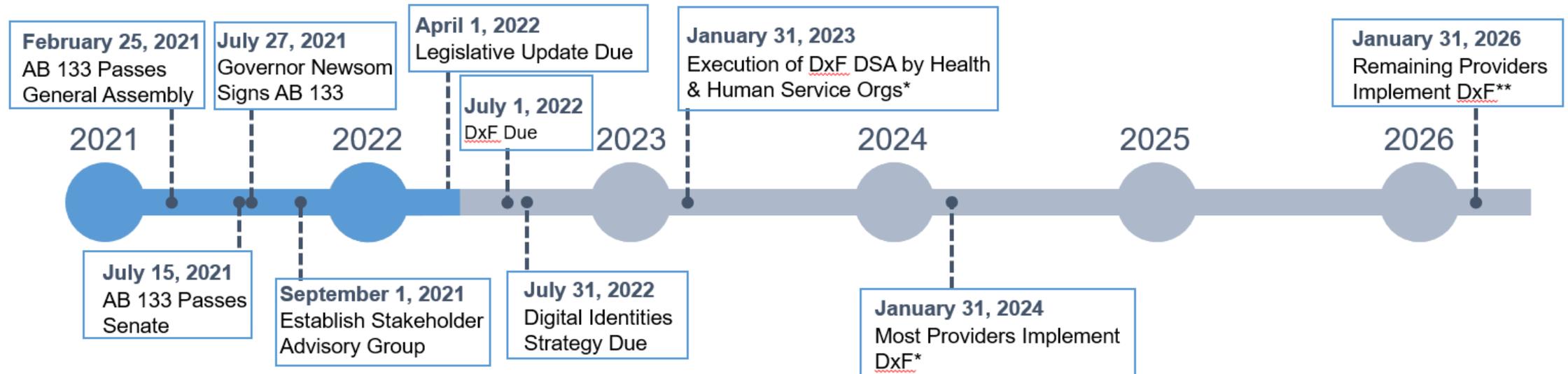


1. Consider the **structure and implementation of the DxF governance model**
2. Discuss potential opportunities to **address regulatory and policy gaps**
3. Discuss a draft of the **digital identity strategy**
4. Provide a **Data Sharing Agreement Subcommittee update**

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

California Health & Human Services Data Exchange Framework – **Considering Potential Governance Models**

AG6 Governance Discussion Recap – *Governance Functions*

CalHHS made the following updates, based on AG member input, to the governance functions reviewed during our previous meeting.

Key clarifications and revisions to the governance functions include:

- **Function #5: Enforcement and monitoring compliance with P&Ps, requirements and guidelines**
 - The state should conduct additional stakeholder engagement and release the DSA P&Ps before establishing formal enforcement processes
 - Data Exchange Framework oversight authority and role needs to be aligned with other state agencies as different stakeholders subject to AB 133 are regulated by different state agencies.
- **Function #7: Program development and financing**
 - Program evaluation should be included in order to track progress against the goals of AB 133.
- **Function #9: Communications and education**
 - This function should be expanded to include educating consumers about their rights with respect to data sharing and what the Data Exchange Framework will mean for them.
- **General**
 - Integrate the concept that providers can meet their obligations under the DxF by connecting to a Qualified Data Exchange Intermediary

Note: Redlines of the revisions to the governance functions are included in the appendix.

Today's Goal: *Consider the Structure of Effective Governance*

At the last Advisory Group meeting, Members offered differing perspectives on the form of the Data Exchange Framework governance model.

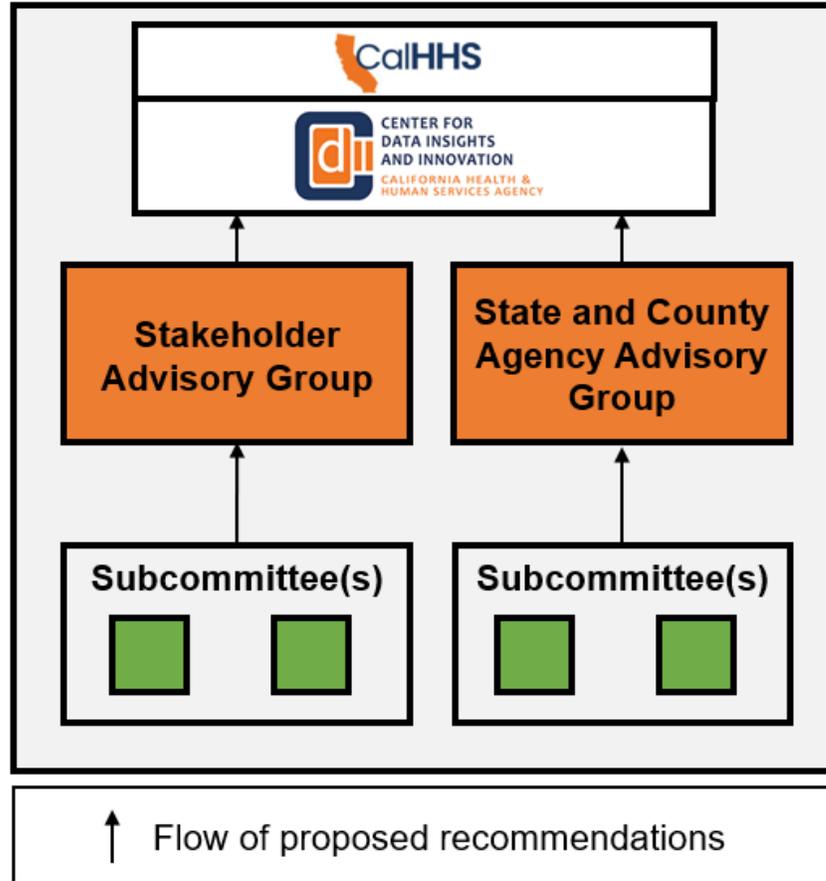
- A few Members voiced concern that AB 133 only authorizes the Advisory Group to assess governance options and not to advance recommendations about the functions and form of governance.
- The majority of Members, however, disagreed with that proposition, and generally agreed on the need for formal governance and the proposed governance functions.

There was not consensus, however, on what form the governing structure should take, and Members requested additional time at the next Advisory Group meeting to discuss further.

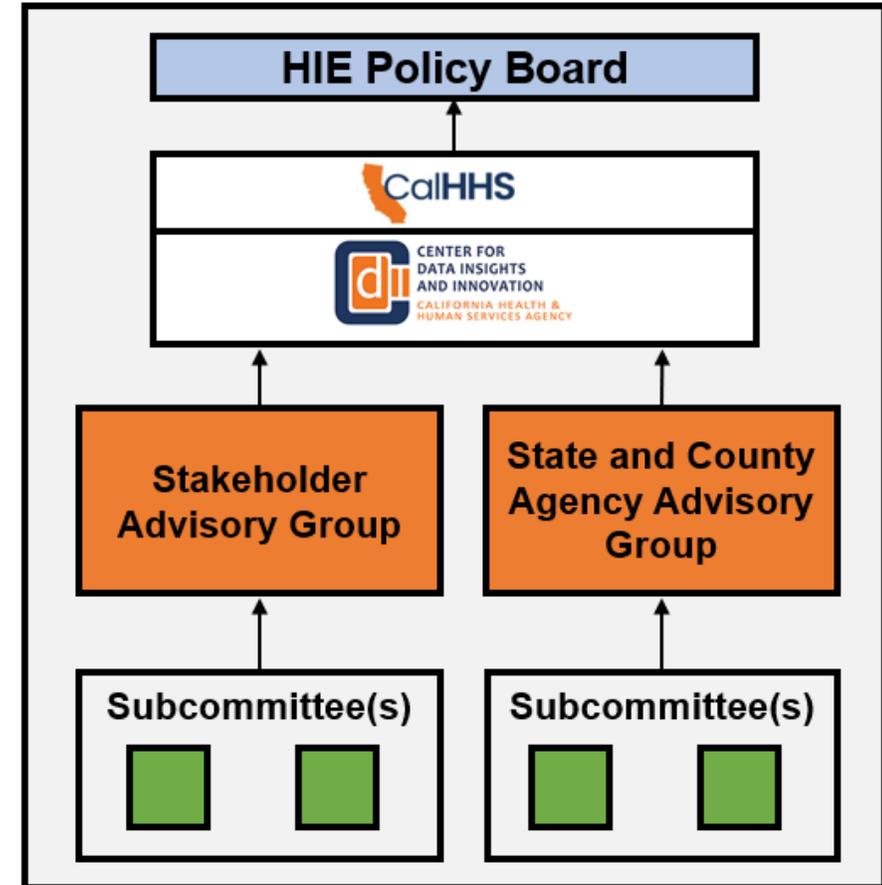
- Members generally agreed that Data Exchange Framework governance to be housed within CalHHS and supported by state government
- Some Members suggested that California consider other forms of governance models including:
 - Models with an oversight board or commission, similar but not necessarily identical to Covered California, to govern the Data Exchange Framework, with members appointed by the governor, Secretary and/or legislature.
 - A hybrid model under which certain governance functions are delegated to an oversight board or commission and others are delegated to CalHHS/CDII.

Governance Model Recommendation

July 1, 2022: Launch the DXF Framework with CDII managing & overseeing all aspects of Governance¹



January 2023: Establish HIE Policy Board with oversight role & CDII administrator role



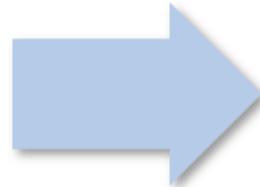
1. Details on all governance structure options provided on the following slides.

Governance Model Recommendation

Establish Interim Governance on July 1, 2022, as defined by Option #1, migrating to Option #2 or #3 in 2023.

July 1, 2022: Launch the DXF Framework in accordance with Option #1

- DxF implementation would be overseen by governance structure as described under Option #1 whereby CDII is responsible for overseeing initial implementation.
- Governance would include external advisory groups to support ongoing development of DXF policy and program recommendations.



January 2023: Establish HIE Policy Board

- CalHHS would develop a statutory proposal that would establish an HIE Policy Board in January 2023.
- External advisory groups would continue to be convened after the Policy Board is established.

Governance Model Examples

California Emergency Medical Services Authority (CalEMSA)	Covered California	Examples of HIE Governance in Other States: NY, MD and MI
Enabling Statute established governance for both institutions		State statute established the HIEs and governance to oversee them
<ul style="list-style-type: none"> Chapter 1260, Section 1799 of the Health and Safety Code created the Commission Effective January 1, 2009, within the CalHHS Commission defined as a 19-member stakeholder board Subsequent bylaws established duties, responsibilities and appeals functions of the Board 	<ul style="list-style-type: none"> AB 1602 and SB 900 established Covered California in September 2010 Statute established a new independent public entity with governed by a five-member executive board Statute specified powers and duties of the new entity and the board governing the Exchange (including adopting regulations) 	<ul style="list-style-type: none"> Statute granted authority of a Policy Board to be housed within a state entity (NY and MD), or create an independent commission to work with state government (MI) State health department retain granted rule making authority in all three states All three states heavily leverage federal funding through departments of health (Medicaid and HITECH) to support and expand HIE capabilities, and leverage health department rolls to align HIE participation incentives All three states have created strong leadership positions within state government to advance HIE priorities

Discussion Questions

- Q Is additional rulemaking authority needed beyond the contracting authority granted under AB133?
- Q What should the scope of powers of a governance entity be?
- Q What are the right attributes of Policy Board members?
- Q Should Policy Board members subject to strict conflict of interest policies?

Governance Model Structures

Current: No Centralized HIE Governance	CalHHS/CDII	HIE Policy Board	Policy Board Hybrid
<ul style="list-style-type: none"> No formal governance model or body is established All governance and oversight functions delegated to CalHHS and CDII with no external stakeholdering process 	<ul style="list-style-type: none"> Advisory groups and subcommittees provide advisory support and advance recommendations Public meetings provide access to stakeholder deliberations and recommendations development 		
	<ul style="list-style-type: none"> Formalizes governance within an existing state agency/department (CalHHS/CDII) 	<ul style="list-style-type: none"> Board members subject to strict conflict of interest policies Legislation would be required to formally establish the HIE Policy Board Advisory groups and subcommittees provide advisory support CDII staff recommend policies to HIE Policy Board for consideration 	
	<ul style="list-style-type: none"> Decision-making, DxF implementation, and oversight authority rests with CalHHS/CDII 	<p>HIE Policy Board comprised of individuals appointed by the governor and legislature have decision-making authority on DxF policies and programs and oversees the implementation of the DxF</p>	<ul style="list-style-type: none"> HIE Policy Board comprised of individuals appointed by the governor and legislature have decision-making authority for limited set of specified activities (e.g., new regulations, identifying public and private sources of funding for programs) CalHHS/CDII have authority for other day-to-day functions and activities (e.g., enforcement actions, developing policies and procedures, establish data exchange standards)

Governance Model Advantages

Current: No Centralized HIE Governance	CalHHS/CDII	HIE Policy Board	Policy Board Hybrid
<ul style="list-style-type: none"> Simplest option to implement with no new governance structures needed to execute the DxF No new legislation needed to establish governance entity or grant new authorities 	Stakeholders able to provide input via advisory groups and subcommittees		
	<ul style="list-style-type: none"> Would be less burdensome than a formal oversight board; allowing for more expedited decision-making and implementation processes Doesn't require additional legislative action – AB 133 already grants CalHHS authority to govern DxF and to enforce DSA requirements 	<ul style="list-style-type: none"> Allows for more transparency and public accountability More permanence since law would institutionalize the HIE Policy Board Would provide checks-and-balances on executive decision-making authority and provide a venue for stakeholders to have a decision-making role in program and policy development May have more regulatory levers at its disposal to incentivize HIE participation 	
		More public accountability and transparency than other models	Allows for more rapid actions on functions resting with CalHHS/CDII than if decision-making for all major functions delegated to the Board

Governance Model Challenges

Current: No Centralized HIE Governance	CalHHS/CDII	HIE Policy Board	Policy Board Hybrid
<ul style="list-style-type: none"> Continues the status quo with limited coordination to advance data exchange in CA and maintain the DxF. Limited ability to get input on forward thinking innovative policies and practices. Lacks transparency and accountability with no formal structures for stakeholders to provide input and participate in governance long term More difficult to access federal funding 	<ul style="list-style-type: none"> Stakeholder role is limited to advisement Less transparent and accountable than models with a governing board 	<p>Most administratively cumbersome option, requiring all major decisions to be passed by a voting board.</p>	<p>Complexity in parsing which functions/decisions rest with the HIE Policy Board and CalHHS/CDII</p>
		<ul style="list-style-type: none"> HIE Policy Board adds another layer of administration, requiring additional time and effort for decision making Risk of delays or inactions if HIE policy board cannot achieve consensus CA conflict of interest requirements may complicate selection of board members Passing a law requires additional steps to implement HIE governance 	

Potential Opportunities: **Regulatory and Policy**

Gaps: Regulatory & Policy

Data Exchange Policies. 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.

- i. **Physical and Behavioral Health.** Certain data types, including behavioral health (e.g., mental health, substance use disorder), HIV/AIDS test results, some sexual health information, and information pertaining to minors, are governed by specific federal and state rules and regulations that require patient authorization to disclose information for data sharing purposes.
- ii. **Social and Human Services.** Federal and state rules and regulations may prohibit the exchange of certain types of social and human service data (including housing, food security/support), without patient authorization.
- iii. **Criminal History.** Unlike federal law, California law does not permit the disclosure of some criminal record identifiers for purposes of coordinating care.
- iv. **Public Health Data.** Some public health data may be collected and used only for specified purposes.

These federal and state policies result in a lack of understanding and confusion about what is and is not permissible to exchange with - or without - signed patient data sharing authorization.

Gap: Data Exchange Policies

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)]*

Key Considerations:

Legal protections safeguard the privacy and security of personal information. While critical to ensuring appropriate stewardship of personal information and building trust among exchange partners, these protections can present barriers to meaningful data exchange. A common understanding of when information sharing is permissible is key to effective data sharing.

Key Considerations - Federal Policy

- The Health Insurance Portability and Accountability Act (HIPAA) governs the disclosure of protected health information (PHI) - individually identifiable health information that is created or received by a “covered entity” such as a health care provider or plan. HIPAA often permits the disclosure of PHI for treatment or care coordination purposes. In some cases, HIPAA prohibits PHI from being shared unless the patient who is the subject of that PHI signs a form that authorizes such disclosure.
- 42 C.F.R. Part 2 regulates certain SUD records and provides narrower data sharing allowances than HIPAA (with no exceptions for treatment, payment, or health care operations). Not all SUD records are regulated by 42 CFR, Part 2; the regulation only applies to information obtained by a Part 2 provider that would identify an individual as having or having had an SUD.
- Other federal law govern exchange of SDOH data including U.S. Department of Agriculture statutes, regulations, and guidance limiting disclosures under the Supplemental Nutrition Assistance Program (SNAP, known in California as CalFresh); the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC) program; and other programs.

Key Considerations – State Policy

California has enacted health privacy laws that exceed HIPAA standards in some cases:

- The California Confidentiality of Medical Information Act (CMIA) imposes requirements that go beyond HIPAA, such as additional restrictions related to authorization forms.
- California also has an SUD confidentiality law, Health and Safety Code Section 11845.5, which mirrors 42 CFR Part 2 in many respects but applies to a broader class of providers.
- Other state laws that offer data protections to specific classes of data include, but are not limited to:
 - Welfare and Institutions Code Section 5328 – the Lanterman-Petris-Short Act’s privacy provision which applies to records held by private, state, and county mental hospitals and hospitals for the developmentally disabled, and includes distinct disclosure and consent requirements
 - Health and Safety Code Section 120985 (HIV test results)
 - Welfare and Institutions Code 10850 (public social service records)
 - Laws that may prevent the disclosure of inmates’ release dates and other inmate information

Steps have been taken to improve alignment between state and federal law, and to provide state policy guidance:

- Example: To support the implementation of CalAIM, AB-133 permits participating entities, “notwithstanding any other state or local law”, to share data “to the extent necessary to implement applicable CalAIM components...to the extent consistent with federal law”.
- Example: CalOHII released multiple volumes of the [State Health Information Guidance \(SHIG\)](#) to clarify federal and state laws that affect disclosure and sharing of health information.

Potential Opportunities - Regulatory & Policy

Development of 'Universal' Release of Information Authorizations

Broad-based adoption and use of a 'universal' release of information authorization form may improve consistency of collecting and managing authorizations, reduce administrative burden, and reduce barriers to data sharing across sectors.

Example: Michigan requires all Medicaid providers who are requesting release of behavioral health and/or substance use disorder related information to “accept, honor, and use [a] [standard consent form](#) in cases when such consent is required”.

Discussion Questions

- What is the ideal scope of the consent form? Should it address sharing of information related to physical, behavioral, and/or social services?

Potential Opportunities - Regulatory & Policy

Consideration of a Consent Management Solution / Registry

A consent management service could improve care coordination and continuity of care for individuals as well as reduce burden on health care entities in terms of obtaining and managing authorizations to release and share data.

Example: CRISP, the designated HIE serving the District of Columbia was [awarded a grant by DC's Department of Health Care Finance to develop a granular consent management solution](#) to facilitate the exchange of SUD data protected by 42 CFR Part 2. Stewards of Change Institute's [Project Unify](#) provides another example of early efforts to implement a consent management solution.

Discussion Question

- If a consent management service is established, who should have oversight and management responsibilities?

Public Comment Period

Digital Identity Strategy Update

Requirement of AB-133

By July 31, 2022,
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.”

Methodology

Use focus groups to gain input from specific stakeholder perspectives on a strategy for digital identities:

- Health information exchanges
- Consumer privacy
- Health care providers
- Health plans
- Social service organizations
- State health and human service departments

- Conducted twelve 90-minute focus group meetings in February and March
- Discussed aspects of the digital identity strategy with DSA Subcommittee
- Summarized process for the Advisory Group in December and January, and concepts of the emerging strategy in March
- **Bring a draft strategy to the Advisory Group to today's meeting**
- Revise strategy with Advisory Group comments, public comment, additional focus group input if needed in April and May

Application of DxF Principles

1. Advance Health Equity 3. Support Whole Person Care	– Discussed how digital identities might be used to assess equity and access – Considered bidirectional use by both health and human services organizations
2. Make Data Available to Drive Decisions and Outcomes 7. Adhere to Data Exchange Standards	– Emphasized compatibility with federal standards
4. Promote Individual Data Access	– Considered identity needs to support consumer access
5. Reinforce Individual Data Privacy and Security 6. Establish Clear & Transparent Terms and Conditions 7. Accountability	– Discussed permitted uses, security (including with DSA Subcommittee) – Considered privacy when identifying attributes

Definitions

Digital Identity: collection of attributes that establishes an identity associated with a real person in a specific context, in this case for the Data Exchange Framework

- *May include a digital credential used for identity and access management*

Unique Digital Identity: digital identity that uniquely identifies an individual

- *A digital credential (e.g., login and password) uniquely identifies an individual*
- *Other attributes unique to an individual can be used to establish uniqueness*

Secure Digital Identity: digital identity that is protected against unauthorized access or modification, or intentional or unintentional loss or corruption

Private Digital Identity: digital identity that is collected, used, and shared only in allowed ways for allowed purposes with trusted individuals in order to protect personal privacy

Master Person Index (or MPI): database or service that aggregates and cross-references identities across different organizations, systems, and contexts

Relevant National Initiatives

CARIN Federated Digital Identity¹

- Focuses on developing a trust among issuers of digital credentials, relying parties
Framework for federating trusted Identity Assurance Level 2 certified credentials across health care organizations
- Use Cases
 - 1) Consumers accessing and aggregating their health information
 - 2) Organizations verifying the identity of an individual accessing the health information online
 - 3) Selective sharing and management of authorization

FAST Reliable Patient ID Management²

- 1) Mediated Patient Matching: match through 3rd party authoritative for patient identity
 - Using name, DOB, gender, address
 - Optionally add insurance ID, etc.
- 2) Collaborative Patient Matching: patient carries unique identifier that can be used to access information from issuing organization
 - Include name, DOB in addition to issued identifier
 - Exchange requestor's identifier to use in subsequent queries
- 3) Distributed Identity Management: patient provides information used in patient matching or record linking (not yet formed)

Purpose / Use Case (1 of 2)

Associating exchanged health and social services information with correct real person

“patient matching”, “person resolution”, “record linking”

- Per AB-133, for treatment, payment, or health care operations
- Specify all allowed purposes in the DSA
- Afford the same privacy and security requirements as health information

But Not

- Demographic information for other purposes
 - AB-133 calls for support of MPIs
 - Primary need is improved statewide patient matching and record linking
- Development of a "golden record"
- Establishing credentials for patients to access their own data
 - Perhaps a future consideration
 - Monitor CARIN/DHHS pilot for federated digital identity
- Prohibition of exchanging demographics in USCDI for other purposes as required by AB-133
 - Serves a different purpose of informing DxF participants about patients

Purpose / Use Case (2 of 2)

Associating exchanged health and social services information with correct real person

“patient matching”, “person resolution”, “record linking”

- For scenarios anticipated for the DxF
 - care coordination
 - population health
 - emergency response
 - public health response
 - transitions from incarceration

However

- Demographics in digital identities may not be used to stratify populations for analysis purposes
 - Organizations have that information on their populations already
 - Digital identities may be used to gather information on individuals stratified by other means if allowed by the DSA

Definition of Digital Identity (1 of 3)

Selected "Patient Demographics" attributes from the USCDI v1

- Name
- Date of birth
- Address
- Previous address(es)
- Phone number(s)
- Email address(es)

Demographics are generally only potentially unique in aggregate

Additional unique identifiers

Choose identifiers uniquely associated with one and only one real person

- State or federal identifiers related to health
 - E.g., Medi-Cal ID, Medicare ID
- IDs from other health-related state programs
- Expand to include IDs from other social services-related state programs as social services become participants in DxF
- Local identifiers related to health
 - E.g., health plan member ID(s), medical record number(s)

Definition of Digital Identity (2 of 3)

Patient Demographics

- Name
- Date of birth
- Address
- Previous address(es)
- Phone number(s)
- Email address(es)

Additional unique identifiers

- Identifiers from health-related federal and state programs
- Identifiers from social services-related state programs
- Local identifiers related to health

But Not

- Race, ethnicity, or preferred language
 - Not consistently reported
 - Not high value in patient matching or record linking
 - Some populations may be reluctant to share
- Previous name, gender
 - Of limited use in patient matching or record linking
 - May unintentionally identify transgender individuals
- State or federal IDs not related to health
 - Some populations may be reluctant to share
 - May present a greater target for identity theft
- USCDI v2 or v3 demographics
 - Of limited use in patient matching or record linking
 - Not widely implemented

Definition of Digital Identity (3 of 3)

Patient Demographics

- Name
- Date of birth
- Address
- Previous address(es)
- Phone number(s)
- Email address(es)

Additional unique identifiers

- Identifiers from health-related federal and state programs
- Identifiers from social services-related state programs
- Local identifiers related to health

Tokenizing

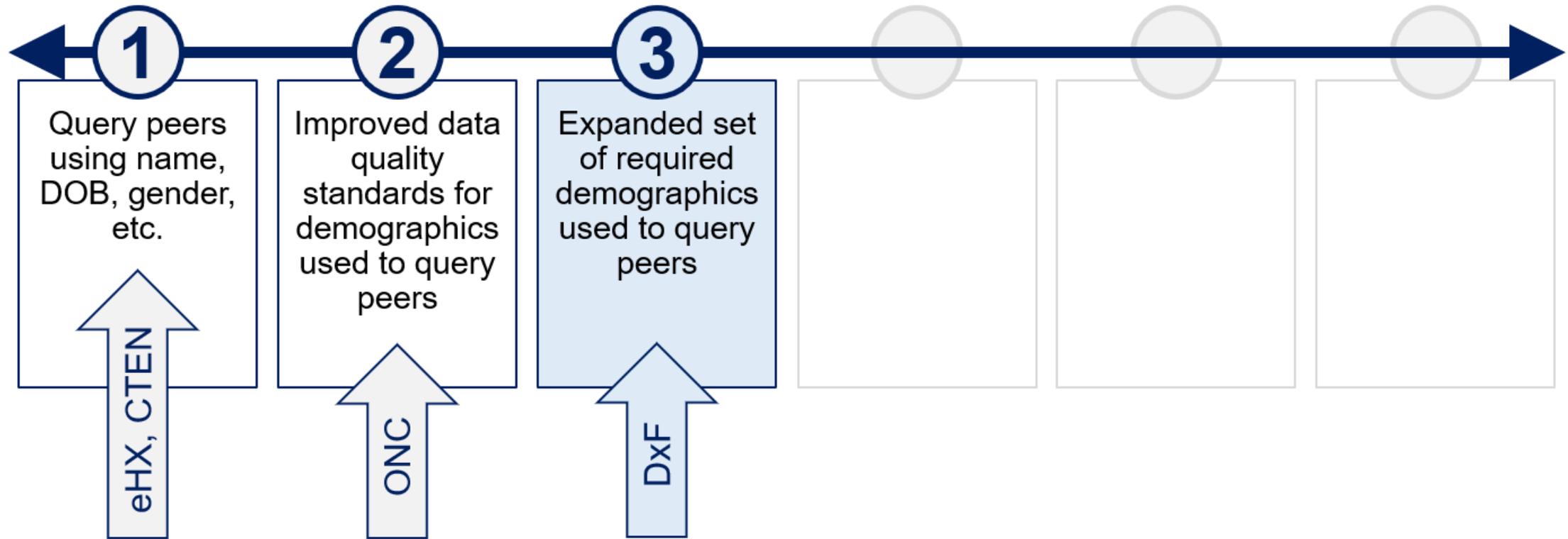
A process of exchanging sensitive data with non-sensitive data without losing its business utility

- Provides additional protection against identity theft
- Avoids additional privacy concerns
 - E.g., revealing member IDs for self-pay
 - E.g., participation in some programs
- Tokenize all unique identifiers if/when infrastructure can be made available
- May allow use of state and federal identifiers not related to health

Standards for Digital Identity Attributes

- Adopt standard formats and datasets specified in USCDI v1 or other nationally-recognized standards
e.g., USCDI v1
- Adopt additional standard formats and datasets promoted by federal initiatives
e.g., Project US@
- Develop additional standard formats and datasets for use in the DxF where absent
e.g., format for family name containing multiple words
 - Harmonize standards where conflicts exist
 - Develop standards where none exist as a function of data governance
 - Promote creation on nationally-recognized standards were absent
 - Transition to standard formats and datasets as federal initiatives mature and nationally-recognized standards emerge

Use of Digital Identities Alone



Permitted Uses

- Impose security, consent, audit requirements via DSA equal to health information
- Limit use via DSA to linking health and social services information to correct real person or searching for information in an organization participating in DxF exchange
 - Secondary uses are not permitted (e.g., using contact information for outbreak investigation or address to stratify populations for healthcare access or equity analysis)
 - Attributes that could be gleaned from digital identities must be requested subject to permitted purposes
- Limit disclosure in DSA of digital identities to minimum necessary for matching/linking
 - Sharing of demographic attributes not already known to the entity is not allowed
 - Sharing of local identifiers is allowed only for permitted purposes under the DSA
- Users must be signatories to the DSA
 - DSA imposes security and privacy controls

Statewide Person Index (1 of 3)

Explore funding and sustainability plan for a statewide person index

Purpose

- Collect attributes associated with a digital identity
- Cross-reference local identifiers
- Facilitate identifying
 - local identifiers or
 - more complete demographic searchesfor matching digital identities
- Mapping digital identities to orgs

- AB-133 requires digital identities to support master patient indices [sic]
 - Not interpreted as a requirement for public or private organizations to implement MPIs
 - Recognizes many organizations already have MPIs that should be supported
- Exchange of information would be enabled by a statewide person index
 - Associating exchanged information to the correct real person
 - Matching and merging digital identities among organizations with MPIs
 - Facilitating searches for organizations with information on a given person

Statewide Person Index (2 of 3)

Explore funding and sustainability plan for a statewide person index

Purpose

- Collect attributes associated with a digital identity
- Cross-reference local identifiers
- Facilitate identifying
 - local identifiers or
 - more complete demographic searchesfor matching digital identities
- Mapping digital identities to orgs

Perhaps

- A statewide identifier that could be shared among DxF participants
- A statewide identifier that could be shared with the consumer
 - Identifier can be "changed" if compromised
 - Consumers need not apply for a statewide identifier
- Involve consumers in managing their digital identities
 - Considered when implementing consumer access on the DxF
- Service for tokenizing data elements

Statewide Person Index (3 of 3)

Explore funding and sustainability plan for a statewide person index

Purpose

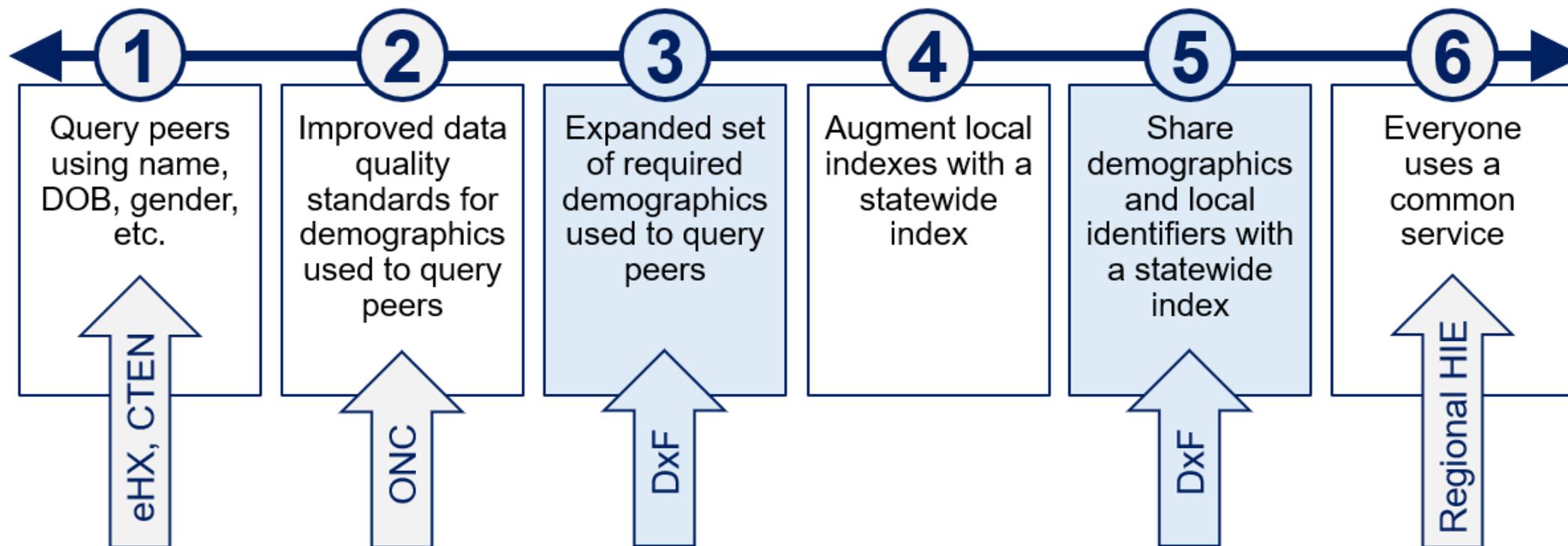
- Collect attributes associated with a digital identity
- Cross-reference local identifiers
- Facilitate identifying
 - local identifiers or
 - more complete demographic searchesfor matching digital identities
- Mapping digital identities to orgs

But Not

- A replacement for existing MPIs that all must use
- A golden record for demographic data
- Initially, identity proofing or process to issue credentials used by a consumer for accessing their information on the DxF
- A database of contact information
 - Prohibited by the DSA

A statewide index is a target for identity theft and will require significant security controls

Use of a Statewide Index



Enhanced by support for organizations with an MPI

Related Concepts

Beyond the strategy for digital identities but often discussed in context of identity

Statewide Consent Registry

- Identity often associated with consumer authorization to exchange their information
 - Consent is not part of the strategy, but may be facilitated by it
 - A consent registry is critically dependent upon reliable identity
-

Statewide Provider Index

- Exchange is facilitated by common understanding of how to exchange with participants
 - A provider directory is beyond the scope of digital identities
-

Statewide Record Locator

- Exchange might be facilitated by a service that identifies what information is available where
 - A record locator is not part of the strategy
 - A record locator is critically dependent upon reliable identity
 - Local identifiers at an organization may provide useful hints as to where information may exist
-

Potential Burdens

Acknowledge that the gains of digital identities may transiently increase burden

Existing national standards for patient discovery may not fully support all attributes in the digital identity

Existing EHRs and other systems may not fully support all attributes of digital identity

A statewide index will require significant funding and effort

Mitigation

- Align with federal standards whenever possible
- Advocate for new elements in nationally-recognized standards
- Provide runway for adoption
- Ensure that there is value in strategy to incentivize adoption
- Provide runway for adoption
- Investigate opportunities for sustainable funding
- Engage stakeholders in continued development and planning
- Obtain advantages of defining digital identities and standards until a statewide index can be created

Summary

- 1) Adopt as purpose patient matching and record linking, investigating need for credentials in the future
- 2) Adopt standard set of attributes comprising a digital identity, including selected demographics and health-related unique identifiers
- 3) Consider privacy in selection of attributes comprising digital identities
- 4) Tokenize sensitive data as soon as capability exists
- 5) Protect privacy and security equally as health information in the DSA, for health organizations bound by HIPAA as well as social services that are not
- 6) Limit purposes to associating data with a real person, prohibiting secondary uses
- 7) Create a statewide index if sustainable funding can be identified

Next Steps

Status	Activity / Milestone
Jan	Assess DxF participant needs; explore overarching approaches
Feb & Mar	Explore strategy components
Mar	Refine strategy components with emphasis on privacy, security
Apr	Complete a draft strategy
May	Refine strategy with AG; align potential requirements with DxF, DSA
Jun/Jul	Finalize strategy for delivery to legislature (June or July 2022)

- 1) Submit comments no later than April 15, 2022**
- 2) Participate in public comment period in late April and/or early May
- 3) Review revised strategy at AG meeting on May 18, 2022

Discussion Questions

1) Is this an appropriate first step?

Will this strategy help us meet the vision of the Data Exchange Framework?

2) Is there value in specifying attributes in the absence of a statewide index?

Will use of a common set of attributes and the standards used to specify them improve exchange?

3) Must we adopt national standards even if they don't meet our needs?

For example, Patient Discovery standards require that gender be specified, but we may remove it as an attribute for privacy reasons

4) Should the state operate the statewide index (if created)?

Will consumers trust the state with information about them?

Data Sharing Agreement (DSA) Subcommittee Update

DSA Subcommittee Status Update

Purpose

Support the CalHHS's Data Exchange Framework Stakeholder Advisory Group's development of recommendations for the creation of California's Data Sharing Agreement ("DxF DSA") as required by AB133.

Status Update

The DxF DSA Subcommittee met on March 22nd for its fifth meeting. At this meeting, the DSA Subcommittee discussed: (1) the digital identities strategy and connections to the DSA and its policies and procedures (P&Ps); (2) approach for DxF and P&Ps development; and (3) draft versions of the third set of DxF DSA topics.

DSA Subcommittee Members and the public provided feedback on:

- **Digital identities concepts** regarding privacy and security requirements
- **DSA topics** including: (1) the concept of a qualifying intermediary; (2) uses and disclosures; and (3) minimum necessary.

DxF DSA and Policies & Procedures Development

By July 1, 2022, AB 133 requires the establishment of a single data sharing agreement and a common set of policies and procedures that govern and require the exchange of health information.

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

Approach for P&Ps Development

The DxF DSA Policies and Procedures will be developed and released on a rolling basis.

Foundational P&Ps

On July 1, 2022, CalHHS will release an initial set of **foundational P&Ps**.

Additional P&Ps

After July 1, 2022, CalHHS will release **additional P&Ps** to support DxF DSA implementation.

The additional P&Ps will be developed under the DxF governance approach as determined by CalHHS and the Stakeholder Advisory Group.

P&Ps to be Released by July 1, 2022

1. Governance and Accountability

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

2. Technical Specifications

- ❖ Data Elements to Be Exchanged

3. Privacy and Security

- ❖ Breach Notification

4. Operations

- ❖ *Requirement to Respond (Tentative)*

DxF DSA and P&Ps Milestones

The DSA Subcommittee continues to provide input on design concepts and considerations for the DxF DSA and P&Ps. Full drafts will be discussed at AG8 and released for public comment in May 2022.

Status	DSA SC Meeting	Activity / Milestone
✓	1	Convene DSA Subcommittee; discuss subcommittee purpose and existing data sharing agreements
✓	2	Discuss key considerations and threshold questions for DxF DSA development
✓	3	Preview draft DxF DSA outline; discuss draft language for first set of topics
✓	4	Discuss draft language for second set of topics
✓	5	Discuss digital identity strategy and draft language for third set of DxF DSA topics
Apr 26	6	Discuss proposed drafts for public comment of DxF DSA and initial set of P&Ps
May 11*	NA	Share full drafts of the DxF, DxF DSA, and initial set of P&Ps with the AG
May 18*	NA	Release full drafts of the DxF, DxF DSA, and initial set of P&Ps for public comment
Jun 1*	NA	Public comments due for the draft DxF, DxF DSA, and initial set of P&Ps
Jul 1	NA	Release of the DxF, DxF DSA, and initial set of P&Ps

Closing Remarks

Progress and Next Steps

Status	Step
✓	Convene DxF Stakeholder Advisory Group (AG)
✓	Convene AG Data Sharing Agreement Subcommittee
✓	Identify key barriers to data exchange across technical infrastructure and standards, financing and business operations, and regulatory and policy domains
✓	Establish guiding principles for health and human services data exchange in California
✓	Provide feedback on options for resolving infrastructure gaps (HIT)
✓	Provide feedback on resolution options for standards and consumer access gaps
✓	Provide feedback on a potential governance model
✓	Provide feedback on a potential governance model and for resolving regulatory and policy gaps
5/18	Provide feedback on elements of draft DxF and DSA
6/23	Review updates to the draft DxF and DSA based on submitted feedback

Next Steps

CalHHS will:

- Summarize and post meeting notes in advance of next meeting.
- Consider feedback on the potential governance model and potential opportunities to address regulatory and policy barriers.
- Develop materials to support our next working session (i.e., DxF and DSA drafts).

Members will:

- Provide feedback on proposed governance model and regulatory and policy opportunities by April 14th.

Advisory Group Workplan & Meeting Schedule

#	Date	Proposed Topics
8	May 18, 2022	DxF and DSA Review
9	June 23, 2022	DxF and DSA Feedback Review

For more information or questions on Stakeholder Advisory Group meeting scheduling and logistics, please email Kevin McAvey (Kmcavey@manatt.com).

Appendix: Governance Goals and Functions

- Includes **redline updates** made based upon stakeholder input during and after the March 3rd, 2022, Stakeholder Advisory Group Meeting

Overview of Draft Governance Model

1 Purpose and Goals of Governance Structure

2 Governance Legal and Contractual Framework

3 Core Governance Functions

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.

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	

Core Governance Functions (1-2)

1. Harmonization of state law with federal law

- Facilitate and oversee a process to identify state laws, regulations, P&Ps and guidelines that may conflict with federal law and that prohibits (or creates ambiguity and uncertainty that stymies) secure data sharing
- Advance policy proposals to refine rules and policies and advance proposals to legislative leaders to amend or establish state law as needed.
- Identify challenges with federal law and regulations and develop approaches to engage with federal partners to resolve conflicts or issues (e.g., HRSA and USCDI v2 data standard conflicts)

2. Development of and modifications to DSA Policies and Procedures (P&Ps)

- DSA P&Ps should cover topics that are expected to evolve over time
- P&Ps should be developed and updated accordingly, potentially topics may include:
 1. Privacy, security, and data sharing consent requirements
 2. Exchange purposes – permitted purposes vs. prohibited purposes
 3. Event notification policies
 4. Data quality
 5. Authorizations
 6. Individual Access Services
 7. Minimum technical requirements
 8. Other minimum requirements, e.g., insurance, including cyber liability coverage
 9. Dispute resolution process
 10. Others as identified by state governance and its committees

Core Governance Functions (3-4)

3. Enactment of data sharing P&Ps and Requirements

Develop and institute requirements that cover topics of more permanency than DSA P&Ps and may include:

- Obligation to cooperate with respect to the Data Exchange Framework
- Non-discrimination – including restrictions from prohibiting or impeding exchange with other health and human service entities
- Obligations to provide notification of any adverse security events
- Others as defined by CalHHS

4. Review of Federal standards and national efforts impacting data exchange

- Identify gaps and consider opportunities to expand upon federal standards and policy – where federal standards/policies fall short or have not been developed.
- Engage with federal agencies regarding updates to federal standards and policies and advance policy recommendations to Federal agencies, including CMS, OCR, CDC and others.

Core Governance Functions (5-6)

5. Enforcement and monitoring compliance with P&Ps, requirements and guidelines

- **Monitor compliance** with DSA policies and procedures, requirements and guidelines and other, state policy, and identify and address breaches or non-compliance, potentially through attestations, audits, grievance processes and other mechanisms.
- **Enforcement:** respond to breaches or non-compliance with DSA P&Ps, requirements and guidelines and other state rules, potentially with sanctions and remedies, that may include monetary penalties, remediation plans, and/or suspension of participation.
 - Enforcement process should include a process for appeals
 - The state would conduct additional stakeholder engagement and release the DSA P&Ps before establishing formal enforcement processes
- DxF oversight authorities will be aligned among different state agencies, to the extent possible, as different stakeholders subject to AB 133 are regulated by different state agencies.

6. Oversee dispute resolution and grievance processes

- Regular discussion of any widespread issues affecting the Data Exchange Framework.
- Oversee dispute resolution and grievance processes set forth in P&Ps, requirements and guidelines

Core Governance Functions (7)

7. Program development and financing

- Identify areas of need and growth and opportunities to expand HIE
 - Identify additional priority exchange activities
 - Develop HIE use cases to be integrated into programs, P&Ps, requirements, guidelines and contracting requirements
 - Consider need and potential changes to privacy and security laws and regulations in order to inform modification of privacy and security policies and procedures
 - Develop SDOH and demographic/SOGI data collection and use incentive programs
- Establish framework and parameters for programs to support the adoption and implementation of the Data Exchange Framework
 - Technical assistance for small/under-resourced providers (e.g., to support organizations' adoption of EHRs)
 - Establish incentive programs across public and private payers aligned with use case priorities and with consistent terms and requirements (e.g., potential EHR and HIE onboarding incentive programs)
- Develop and approve annual strategic plans **that evaluate implementation progress** and set forth goals, priorities and budget requests
- Support activities that enhance interagency and inter-departmental data sharing practices and activities

Core Governance Functions (8-9)

8. Identification and qualification of exchange intermediaries

- Identify entities and intermediaries who meet minimum state requirements and can support data exchange
- Establish, revise and oversee compliance with requirements intermediaries must meet to qualify, receive state funds, and help DxF participants meet their obligations under the DSA. Examples include:
 - Form of entity and state of organization
 - Consider how qualifying requirements should address national exchange intermediaries such as CareQuality
 - Minimum assets and/or services
 - Minimum insurance requirements
 - Attestations to conform with DSA policies and procedures and other state requirements and guidelines

9. Communications and education

- Market and promote the Data Exchange Framework to encourage adoption and usage
- **Educate consumers about their rights with respect to data sharing and what the DxF means for them**
- Develop best practices regarding the Data Exchange Framework via informational guidelines
- Report on participation and new developments
- Connect needs and support requests with available resources and tools

Core Governance Functions (10-11)

10. Ongoing review of the Data Sharing Agreement

- Review and approve necessary or recommended amendments to form Data Sharing Agreement and related SPG
 - Evolution of state and federal law and implication for California DSA policies
 - Reassess any thresholds or minimum requirements set forth in the Data Sharing Agreement

11. Coordination with other branches of state and local government

- Develop processes and policies to share data between other CalHHS departments and other state agencies
- Coordinate with licensing agencies to develop policy and procedures and support enforcement of Data Sharing Agreement requirements for signatories – including for example updates to provider directory information and provider credentials (e.g., endpoints)
- Develop processes and support inclusion of county and local health, public health, and social services agencies, as part of the Data Exchange Framework, to assist both public and private entities to connect through uniform standards and policies.