Data Exchange Framework Stakeholder Advisory Group Meeting #9

California Health & Human Services Agency

Thursday, June 23, 2022
10:00 a.m. to 1:00 pm

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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 Jocelyn Torrez (jocelyn.torrez@chhs.ca.gov) with any technical or logistical questions about onsite meeting participation.

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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.

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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”

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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** • *John Ohanian, Chief Data Officer, California Health and Human Services*
10:05 AM	**Vision and Meeting Objectives** • *Dr. Mark Ghaly, Secretary, California Health and Human Services*
10:15 AM	**Data Sharing Agreement and Policy and Procedures Updates** • *Helen Pfister, Partner, Manatt Health Strategies*
11:30 AM	**Public Comment**
11:45 AM	**Data Exchange Framework Updates** • *Jonah Frohlich, Senior Managing Director, Manatt Health*
12:00 PM	**Digital Identity Strategy Updates** • *Dr. Rim Cothren, Independent HIE Consultant to CDII*
12:15 PM	**Data Exchange Framework Implementation** • *Dr. Mark Ghaly*
12:55 PM	**Closing Remarks and Next Steps** • *John Ohanian*

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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 *designated by Greg A. Adams*	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 *designated by Don Crane*	Associate Medical Director	MedPoint Management (representing America's Physician Groups)
Joe Diaz *designated by Craig Cornett*	Senior Policy Director and Regional Director	California Association of Health Facilities
David Ford *designated by Dustin Corcoran*	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

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Advisory Group Members

Stakeholder Organizations (2 of 3)

Name	Title	Organization
Michelle Gibbons *designated by Colleen Chawla*	Executive Director	County Health Executives Association of California
Lori Hack	Interim Executive Director	California Association of Health Information Exchanges
Matt Legé *delegate for Tia Orr*	Government Relations Advocate	Service Employees International Union California
Sandra Hernández	President and CEO	California Health Care Foundation
Cameron Kaiser *designated by Karen Relucio*	Deputy Public Health Officer	County of San Diego (representing the California Conference of Local Health Officers)
Andrew Kiefer *designated by Paul Markovich*	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 *designated by Anthony E. Wright*	Deputy Director	Health Access California

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Advisory Group Members

Stakeholder Organizations (3 of 3)

Name	Title	Organization
DeeAnne McCallin *designated by Robert Beaudry*	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
Eduardo Martinez *designated by Art Pulaski*	Legislative Director	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 *designated by Nancy Bargmann*	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

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Advisory Group Members

State Departments (2 of 2)

Name	Title	Organization
Dana E. Moore	Deputy Director, State Registrar, & Chief Data Officer	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 *Designated by Diana Toche*	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.

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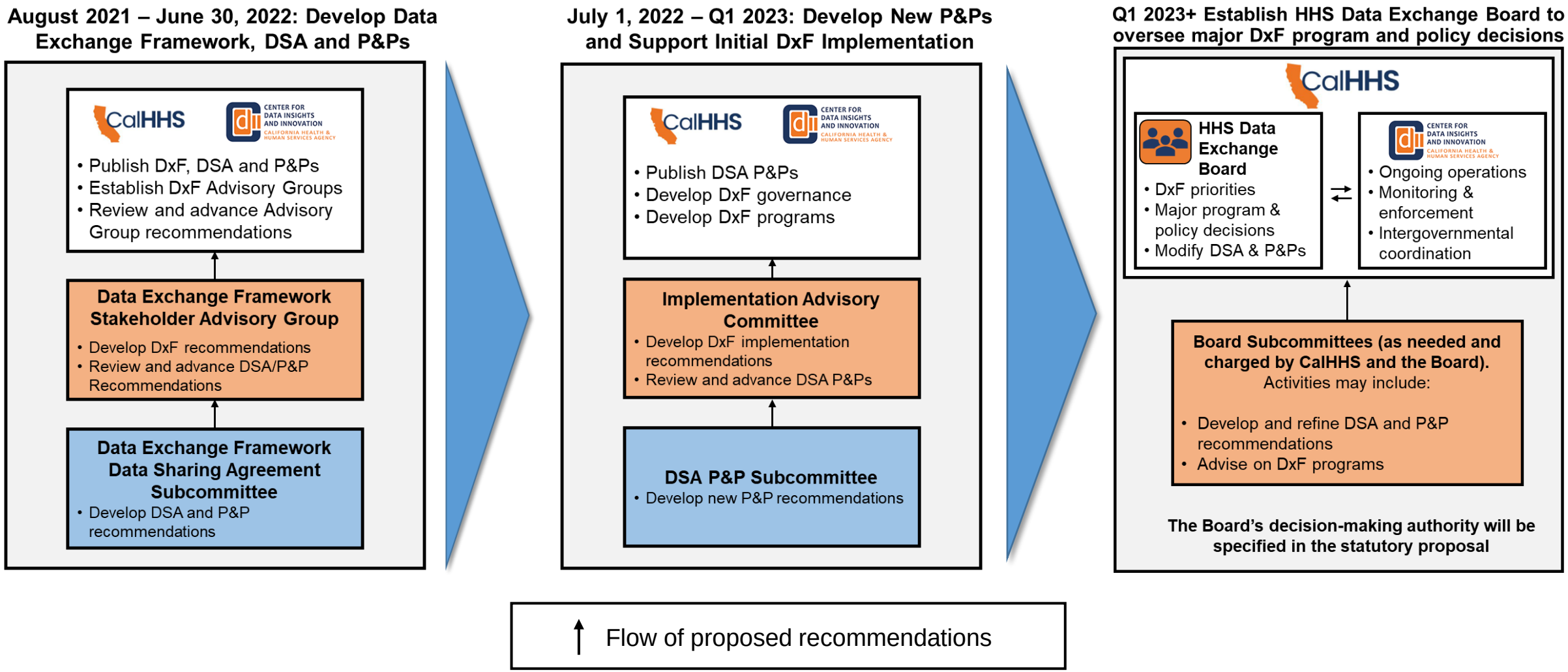
DxF Implementation Overview



Meeting #9 Objectives

1. Provide an overview of the updates to the draft **Data Sharing Agreement** and **initial set of Policies and Procedures** based on public comment
2. Provide an overview of the updates to the draft **Data Exchange Framework Component Documents** based on public comment
3. Provide an overview of the updates to the draft **Strategy for Digital Identities** based on public comment
4. Discuss **DxF implementation after July 1st**

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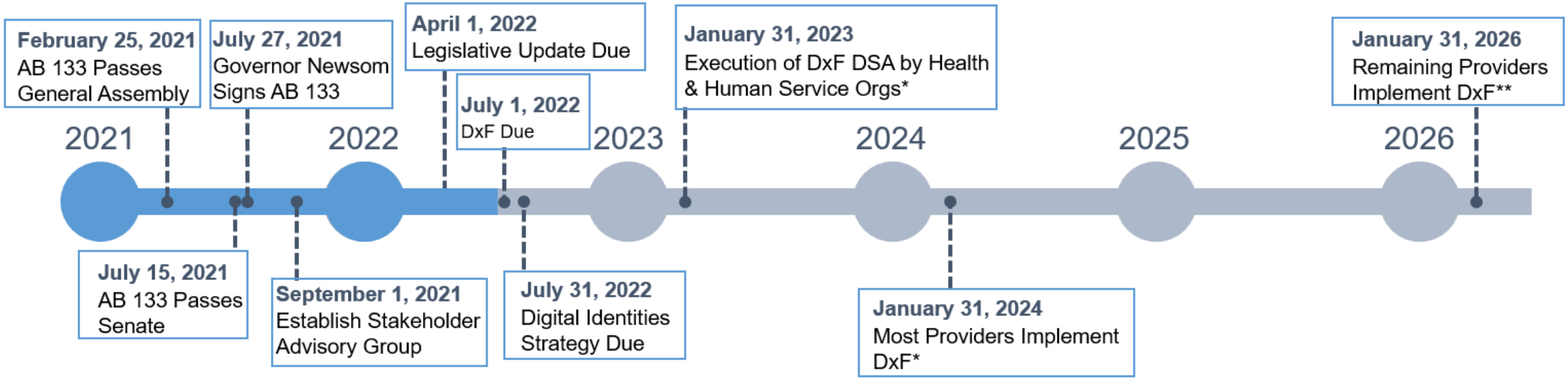
Statutory Requirements & Timeline

AB 133 put California on the path to building a Health and Human Services Data Exchange Framework 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

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Summary of Comments Received

CalHHS received 749 public comments from 47 unique commenters on the draft DxF, DSA, P&Ps, and Strategy for Digital Identities.*

Document	Number of Comments	Number of Commenters
Data Exchange Framework	97	20
Data Sharing Agreement	287	35
Policies & Procedures	242	31
Strategy for Digital ID	123	11

***These numbers include comments received between 4/26 and 6/14 and encompass comments received both during and outside of the formal public comment periods for the respective documents. All comments were reviewed and considered, even those that may not be explicitly referenced during this meeting.**

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Data Sharing Agreement and Policy and Procedures Updates

Data Sharing Agreement (DSA)
Changes to the Draft DSA

Based on feedback from the Advisory Group, the DSA Subcommittee, and the public, substantive modifications to the draft DSA were made to the sections highlighted in red.

DSA Table of Contents

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Sec 3. Definitions

Section Overview

Sets forth the definitions used in the DSA and P&Ps.

Comments

1. Definition of Governmental Participant: Commenters noted that municipalities, counties, and tribal entities are also Governmental Participants.

- **Response**: Revised the definition of Governmental Participant to expressly reference municipalities, counties, and tribal entities.

2. Definition of Social Services: Commenters noted that the definition of Social Services was too limited.

- **Response**: Revised the definition of Social Services to mean "the delivery of items**, resources,** and/or services to address social determinants of health and social drivers of health, including but not limited to housing, **foster care,** nutrition, access to food, transportation, employment and other social needs."

3. Definition of Social Service Organizations: Commenters noted that individual component departments that provide social services, but are part of a larger amalgamated health and human services agency, do not clearly fall under the definition of Social Services Organization.

- **Response**: Revised the definition of Social Services Organizations to expressly include multi-department health and human services agencies.

Sec 3. Definitions… continued

Comments

4. Definition of Authorization: Commenters requested clarity on whether Part 2 data may be exchanged.

- **Response**: Revised the definition of Authorization to include, when applicable, consent requirements as set forth in 42 C.F.R. Part 2

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Sec 4. Use of Health & Social Services Information

Section Overview

- Provides that the purposes for which Participants shall, may, and may not exchange Health & Social Services Information (HSSI) under the DSA are set forth in the Permitted, Required, and Prohibited Purposes P&P.
- Prohibits exchange of HSSI for a Participant's direct or indirect financial benefit.

Comments

1. Direct or Indirect Financial Benefit: Several commentors expressed concern that prohibiting HSSI exchange for indirect or direct financial benefit was too broad and could curtail legitimate use.

➢ **Response**: Removed the prohibition on exchanging HSSI for indirect or direct financial benefit, and instead, revised the Required, Permitted, and Prohibited Purposes P&P to prohibit a Participant from exchanging HSSI with the intention to sell such data.

Sec 5. Policies and Procedures

Section Overview

Requires Participants to at all times comply with the Data Sharing Agreement, the Policies and Procedures, and Specifications.

Comments

1. Health Equity: Commenters expressed concern that Participants should be required to utilize and adopt data standards that best advance health equity.

- **Response**: Added a provision stating that Specifications will set forth standards that advance health equity.

Sec 7. Requirement to Exchange Health & Social Services Information

Section Overview

Requires Participants to engage in the exchange of Health and Social Services Information through:

- Execution of an agreement with a Qualified HIO,
- Execution of an agreement with another entity that provides data exchange, or
- Use of the Participant's own technology

Required Participants that enter into an agreement with another entity to ensure that the other entity enables compliance with the minimum requirements for data exchange set forth in the P&Ps or Specifications.

Comments

1. Participants' Compliance with Minimum HSSI Exchange Requirements: Commenters noted that it will be difficult for a Participant to **ensure** that another entity enables it to comply with the minimum requirements for HSSI exchange set forth in the P&Ps or Specifications.

- **Response**: Revised this section to require Participants to obtain **reasonable assurances** that the other entity enables the Participant to comply with the minimum requirements for HSSI exchange set forth in the P&Ps or Specifications.

2. Requirement to Engage in Real-Time Data Exchange: Many commenters requested a provision stating that Participants must exchange HSSI in real-time.

- **Response**: Revised this section to state that Participants shall engage in the real-time exchange of HSSI in accordance with the timeframes set forth in the P&Ps (*forthcoming*).

Sec 8. Privacy and Security

Section Overview

Requires Participants to maintain a secure environment that supports the exchange of PHI and PII.

Comments

1. Individual User Education: Commenters stressed the importance of patient consent and patient education with respect to the Data Exchange Framework.

- **Response**: Revised this section to encourage Participants to use forthcoming resources developed by CalHHS to help Individual Users understand the benefits of information sharing and for obtaining informed consent.

Sec 10. Individual Access Services

Section Overview

Requires Participants to provide Participants with the right to access their PHI and PII.

Comments

1. Bidirectional Access: Commenters expressed that Individual Users should have the right to inspect and correct discrepancies in their health records and request self-reported information be added to their records

- **Response**: Revised this section to allow for bidirectional access, as set forth in the Policies and Procedures.

Sec 13. Legal Requirements

Section Overview

- Provides that the Governance Entity shall have the right but not the obligation to monitor and audit Participants' compliance with their obligations under the DSA; requires Participants to cooperate with such monitoring and auditing activities unless prohibited by Applicable Law, including by providing complete and accurate information in furtherance of such activities;
- Provides that, to the extent that any such information constitutes Confidential Participant Information, the Governance Entity will hold such information in confidence and not redisclose it except as required by Applicable Law.
- Did not include language regarding individual opt-out.

Comments

1. Enforcement: Commenters emphasized the importance of enforcement mechanisms to ensure trust in the DxF and noted the absence of specifics on an enforcement methodology.

➢ **Response**: Details on enforcement will be set forth in a forthcoming P&P.

2. Individual Choice to Opt Out of Sharing Data: Commenters noted that the DxF should not undermine California's existing protections to opt out of sharing HSSI, especially for individuals seeking sensitive services.

➢ **Response**: Added a new provision expressly stating that the DSA does not prohibit an individual from opting out of having the individual's information exchanged pursuant to the DSA.

Policies and Procedures (P&Ps)
Changes to the Initial P&Ps

Based on feedback from the Advisory Group, the DSA Subcommittee, and the public, substantive modifications were made to the initial P&P drafts highlighted in red.

Initial P&Ps (to be released on July 1st)

1. **Amendment of DSA**
2. Amendment of Policies & Procedures
3. **Breach Notification**
4. **Permitted, Required, and Prohibited Purposes**
5. **Requirement to Exchange Health & Social Services Information**
6. **Privacy and Security Safeguards**
7. **Individual Access Services**
8. **Data Elements to be Exchanged**

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(1) Amendment of DSA

P&P Overview

Sets forth process for amending the DSA, and among other things, provides that upon approval of an amendment, the Governance Entity will circulate the amendment to all Participants for signature at least 45 calendar days prior to the effective date of the amendment, except in the event that a shorter time period is necessary in order to comply with Applicable Law.

Comments

1. Extending Effective Date of DSA Amendments: Commenters noted that Participants may need more time than 45 days to comply with any DSA amendments.

- **Response**: Revised the Policy to provide that any amendment will not be effective until 180 days after circulation to all Participants, except in the event a shorter time period is necessary in order to comply with applicable law.

(3) Breach Notification

P&P Overview

Sets forth definition of Breach and the obligations of Participants in the event of a Breach, including breach notification timelines.

Comments

1. Breach Notification Timeframe: Many commenters requested that the Policy not create timelines for breach notification different than those under existing law.

- **Response**: Revised the Policy to require Participants to notify the Governance Entity and Participants impacted by a Breach as soon as reasonably practicable and within any timeframes required by Applicable Law.

2. Breach Definition: Many commenters requested that the definition of "Breach" be identical to the definition of "Breach" under HIPAA.

- **Response**: Given that the HIPAA definition of "Breach" may not be applicable to all Participants, revised the definition of "Breach" to mirror the definition set forth in California's Statewide Health Information Policy Manual (which is based on both HIPAA and state law).

(4) Permitted, Required, and Prohibited Purposes

P&P Overview

Sets forth the purposes for which Participants shall, may and may not exchange HSSI under the DSA. Among other things:

- Prohibits Participants from charging fees to other Participants for any exchange of HSSI under the DSA
- Includes Public Health Activities as a purpose for which Participants are required to exchange HSSI under the DSA, but excludes activities related to oversight or enforcement or laws, regulations or rules by Governmental Participants from the definition of Public Health Activates.

Comments

1. Clarification on Sharing Part 2 Data: Commenters requested clarification on whether exchange of 42 C.F.R. Part 2 information is prohibited under the DSA and P&Ps.

➢ **Response**: Revised the Policy to clarify that Participants may, under the DSA, exchange any information subject to 42 C.F.R. Part 2, provided appropriate Authorizations are obtained, for any Permitted Purpose.

2. Direct or Indirect Financial Benefit: Commenters stated that the prohibition of data exchange for indirect or direct financial benefit was too broad and could curtail legitimate use.

➢ **Response**: Removed the prohibition on exchanging HSSI through the DSA for indirect or direct financial benefit and instead, added language prohibiting a Participant from exchanging HSSI through the DSA with the intent to sell such data.

(4) Permitted, Required, and Prohibited Purposes… continued

Comments

3. Responding to State Restrictions on Essential Services: Commenters expressed concern that the DSA could force providers to provide HSSI to third parties that may seek to limit or penalize access to abortion, mental health care, and gender-affirming services.

- **Response**: Added a provision stating that Participants shall not access, use, or disclose HSSI through the DSA with the intention to deny or limit access to medical services, including but not limited to contraception, abortion, mental health care, and gender-affirming care.

4. Qualified HIO Prohibition of Charging Fees: Commenters requested clarification on whether the language prohibiting Participants from charging fees to other Participants would prohibit QHIOs from charging fees.

- **Response**: Revised the Policy to clarify that Qualified HIOs are not prohibited from charging fees to Participants who engage in data-sharing activities through the Qualified HIO.

5. Public Health Activities: Commenters noted that Public Health Activities should be expanded to include oversight activities relating to the enforcement of orders and ordinances pertaining to public health matters (e.g., quarantine).

- **Response**: Revised the Policy to narrowly exclude only the following oversight activities: audits; civil, administrative, or criminal investigations; inspections; licensure or disciplinary actions; civil, administrative, or criminal proceedings or actions.

(5) Requirement to Exchange Health & Social Services Information

P&P Overview

Sets forth requirements for Participants to exchange HSSI.

Comments

1. Duty to Respond to Timeline: Commenters requested that the Policy set forth timeframes for when Participants are required to respond to requests for HSSI made under the DSA.

- **Response:** Revised the Policy to state that responses to requests for HSSI shall be made as soon as reasonably practicable, but in any case within any timeframes required by Applicable Law.

2. Effective Date for Small and Safety Net Providers: Commenters asked that the Policy specify when small and safety net providers will need to exchange information under the DSA.

- **Response:** Revised the Policy to state that while all providers set forth in the statute will be required to execute the DSA by 2023, small and safety net providers will not be required to exchange information under the DSA until January 31, 2026. Also revised the Policy to state that prior to that date, small and safety net providers will still be permitted to access HSSI, provided they comply with the DSA and P&Ps.

(6) Privacy and Security Safeguards

P&P Overview

Sets forth the privacy standards and security safeguards Participants must comply with in connection with the exchange of HSSI under the DSA.

Comments

1. Behavioral Health: Commenters requested that the Policy clearly reflect the necessity of complying with laws that govern behavioral health data sharing.

- **Response:** Added a new provision stating that if a Participant exchanges behavioral health information, the Participant shall implement appropriate administrative, physical, and technical safeguards that protect the confidentiality, integrity, and availability of such information in accordance with Applicable Law, including but not limited to, 42 C.F.R. Part 2 and the California Lanterman-Petris-Short Act.

2. Individual User Education: Commenters stressed the importance of patient consent and patient education with respect to the Data Exchange Framework.

- **Response**: Revised the Policy to state that Participants should use forthcoming resources made available by CalHHS to help Individual Users understand the benefits of information sharing and for obtaining informed consent.

(7) Individual Access Services

P&P Overview

Requires Participants to provide Individual Users or their Personal Representatives access to the Individual User's PHI or PII.

Comments

1. Processing Individual Access Services: Commenters noted that existing law imposes limitations on the individual right of access. Commenters also noted that certain provisions in the Policy are based on HIPAA language that is likely to change.

- **Response:** Revised the Policy to require Participants to process Individual Access Services requests in accordance with Applicable Law. Revised the Policy to provide that if a Participant does not maintain the PHI/PII that is the subject of an individual access request, the Participant will direct the patient to the appropriate Participant (if known). Revised the Policy to provide that if the Policy conflicts with a legally-enforceable Business Associate Agreement, the terms of the Business Associate Agreement will control.

2. Removal of "Designated Record Set" Limitation": Commenters noted California has its own set of requirements regarding access, disclosure, and use of data (e.g., right to access under CCPA and CMIA).

- **Response:** Revised the Policy so that Individual Users may access any PHI or PII (not just PHI maintained in a Designated Record Set) maintained by a Participant to the extent permitted under Applicable Law.

(7) Individual Access Services… continued

Comments

3. Bidirectional Access: Commenters expressed that Individual Users should have the right to inspect and correct discrepancies in their health records and request self-reported information be added to their records

Response: Revised the Policy so that Participants that maintain PHI or PII for an Individual User must respond to Individual User requests to add self-reported data to their records and must have a process to correct inaccurate information and for reconciling discrepancies.

(8) Data Elements to be Exchanged

P&P Overview

Participants shall make available or exchange, at a minimum, data as defined in this policy.

Comments

1. Version of USCDI to Require: Commenters separately advocated for USCDI v1 to align with federal regulation, USCDI v2 with SDOH data to align with AB-133's intent to include social services, or USCDI v3 looking forward to latest federal guidance.

- **Response**: Retained USCDI v1 until October 6, 2022, and USCDI v2 thereafter as (1) all EHI is required after October 6, 2022; and (2) inclusion of USCDI v2 SDOH elements better aligns with DxF Principles and AB-133 intent.

2. Define "Held by Entity": Need clarification of "held by an entity", some suggesting definition of "maintained" used in CMS Interoperability and Patient Access final rule.

- **Response**: Modified to require access to or exchange data elements maintained by the entity, adding the CMS definition of "maintained", to align with CMS language for payers and extend the term and definition to all actors.

(8) Data Elements to be Exchanged… continued

Comments

3. Requirements for Participants "Not Listed": Specifically listing social services was confusing; requirements were unclear and will need revision; need for education, communication, transparency in revision.

- **Response**: Adjusted to: (1) exclude singling out social services to reduce ambiguity; (2) focus on USCDI and "information related to the provision of health care services and/or the provision of social services" to align with the DSA; and (3) noted "future revision to this policy [will be] developed through a public and transparent process" per the applicable P&P.

4. Nationally-Recognized Standards: Suggestion to use US DHHS (ONC) Standards Version Advancement Process.

- **Response**: Added definition of "nationally-recognized standards" to be those published in the current version of the Standards Version Advancement Process (which includes USCDI v2) to clarify the meaning of the phrase.

5. DxF-Specific Standards: Neither DxF nor CalHHS should define new standards; need to address terminologies .

- **Response**: Modified to remove "DxF may specify the use of technology standards, implementation guides, or other standards to fill gaps in nationally-recognized standards…" and add "data formats, terminologies, or code sets mandated by California regulation" to retain focus on federal requirements, nationally-recognized standards, and California regulation requirements.

Polices & Procedures
Next Steps

After July 1st, additional P&Ps will be developed through the DxF governance process and stakeholder input.

P&Ps In Development
• Qualified HIO Designation Process • Real-time Data Exchange • Monitoring and Auditing • Enforcement • Information Blocking • Technical Requirements for Exchange

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Public Comment Period

Data Exchange Framework Updates

Data Exchange Framework Sections

Twenty commenters submitted 97 comments on the six DxF sections since they were shared with the AG on May 12th. Sections with substantive revisions are highlighted in red.

DxF Sections (to be released on July 1st)
1. DxF Development Process
2. DxF Guiding Principles
3. CA Data Exchange Landscape
4. Data Exchange Scenarios
5. DxF Governance
6. CA Data Exchange Gaps and Opportunities

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1. Data Exchange Framework Development Process

Section Overview

- An overview of the development process for the DxF document as well as the DSA, P&Ps, and Strategy for Digital Identities.

Public Comments

1. ***Few comments received***.

➢ ***Response***: *No substantive updates to this section.*

2. Data Exchange Framework Guiding Principles

Section Overview

- Core expectations or “rules of the road” that guide the design and implementation of the DxF, DSA, and P&Ps.

Public Comments

1. Support for Principles & Suggestions for Additional Considerations: Commenters offered support for the Principles and suggestions for a variety of considerations for certain providers (e.g., smaller providers, human service, long-term care, and public health) and individuals (e.g., older adults and caregivers and historically marginalized populations).

➢ **Response**: The Section was modified to add income and age to the list of data elements that should be collected, exchanged, and used to identify gaps in care and health disparities and support quality improvement under *Principle 1: Advance Health Equity*.

3. California Data Exchange Landscape

Section Overview

- A review of the history of federal and CA initiatives to advance data exchange and of the current landscape of data exchange in CA.

Public Comments

1. Additional Federal and State Data Sharing Initiatives. Commenters requested the inclusion of several specific federal and state data sharing initiatives.

➢ **Response**: The Section was modified to add descriptions of additional Federal (*Medicaid Enterprise System Funding*) and California (*POLST eRegistry, CalAIM Population Health Management Service, CA Cancer Registry, CA Parkinson's Disease Registry, CURES, CA Health Care Payments Data System*) data exchange systems and initiatives.

2. **Clarifications and Additional Context for Certain Providers and Entities**. Commenters offered clarifications and additional context for a variety of providers (e.g., public health and providers for older adults) and entities (e.g., health plans and HIOs).

➢ **Response:** The Section was modified to include additional context on the impact of data exchange on care for older adults and the current statutory barriers to the sharing of public health data. Clarifications to the subsections on health plans and HIOs were incorporated.

4. Data Exchange Scenarios

Section Overview

- The six data exchange "scenarios" that were presented to the AG.

Public Comments

1. ***Few comments received***.

➢ **Response**: Minor edits were made to align with the edits made to the *California Data Exchange Landscape* section.

5. Data Exchange Framework Governance

Section Overview

- The proposed Data Exchange Framework governance model and implementation approach.

Public Comments

1. **Support for Different Aspects of DxF Governance**. Some commenters offered support for the establishment of a HHS Data Exchange Board, the function of governance in assessing opportunities for alignment between state and federal standards, and for conducting Board, Advisory Committee, and Subcommittee meetings in an open and transparent manner.

➢ **Response:** CalHHS thanks commentors for their support and agrees with the importance of establishing a HHS Data Exchange Board, aligning with federal standards where appropriate, and conducting meetings in an open and transparent manner.

2. **Suggestions on Governance Functions and HHS Data Exchange Board, Advisory Group, and Subcommittee Membership**. Commenters submitted suggestions on which governance functions should rest with CDII vs. the HHS Data Exchange Board and for specific organizations and qualifications (e.g., expertise in HIE or data privacy) to serve on the Board, Advisory Committee, or Subcommittees.

➢ **Response:** Please see the *DxF Implementation Section* for more details on the next steps for the governance model.

6. California Data Exchange Gaps and Opportunities

Section Overview

- A description of gaps hampering robust data sharing in California as well as associated opportunities that can address these gaps.

Public Comments

1. **Regulatory Barriers to Data Sharing.** Commenters emphasized the magnitude of regulatory and legal barriers to data sharing (e.g., laws requiring consents to release information for each use and disclosure).

➢ **Response**: A new opportunity was added under the Data Exchange Law, Regulations, and Policy gap on addressing federal and state data sharing regulatory alignment. The opportunity discusses the need to harmonize data sharing requirements and create protected pathways for data sharing that maintain robust individual privacy protections and consent requirements.

2. **Inclusion and Explicit Reference to Specified Populations and Sectors**. Commenters recommended that select gaps and opportunities be revised to note that various populations and sectors (e.g., behavioral health, counties, social service organizations, aging populations, school-based health) are intended to be encompassed by the language in the gaps and opportunities and to include considerations relevant to such populations and sectors.

➢ **Response:** Several gaps and opportunities were revised to reference specific populations and sectors and clarify the intent to include these populations and sectors.

6. California Data Exchange Gaps and Opportunities

Public Comments

3. **Additional Context on Federal Funding Opportunities.** Some commenters requested more context on federal funding opportunities.

- **Response**: The Health and Human Service Information Exchange Financing section was revised to include additional references to examples of state-submitted funding proposals and statutory funding authorities.

4. **Considerations on Consent Management for Individuals**. Some commenters noted support for the development of a consent management service but noted that such a service may increase burden on individuals to manage their consents and may be difficult to navigate for individuals and populations with limited access and ability to interact with technology systems.

- **Response:** The Consent Management Service opportunity was revised to note that individuals, as well as health and human service organizations, would require support, education, and technical assistance to build trust and enable the transition to electronic modes of consent management that prioritize individual privacy rights and support health equity.

5. **Ongoing Funding to Support Data Exchange.** Some commenters requested stronger language on ensuring ongoing funding for certain actors and sectors (e.g., HIOs) to support data exchange.

- **Response**: CalHHS recognizes the need for resources to support robust data exchange. This need and associated recommendations are discussed across various gaps and opportunities (e.g., those pertaining to EHR adoption, data exchange intermediary onboarding, financing). Additionally, the May revision to the Governor's proposed budget includes substantial support for data exchange priorities including technical assistance and practice transformation.

Digital Identity Strategy Updates

Strategy for Digital Identities

Eleven commenters submitted 123 comments on the Strategy for Digital Identities since it was published for public comment on May 26. Sections with substantive revisions are highlighted in red.

Section	Description
Introduction and Background	AB-133 requirement; gaps identified by the AG related to digital identities; definitions
Process	Development process; application of Guiding Principles; relevant national initiatives
Purpose	Purpose and use case for digital identities within the Data Exchange Framework
Data Attributes	Data attributes comprising digital identities
Data Standards	Data standards for attributes comprising digital identities; introduction of tokenization
Permitted Uses	Discussion of the permitted purposes to be embodied in the DSA / P&Ps
Statewide Person Index	Discussion of potential creation of a statewide person index and related concepts
Potential Burdens	Burdens and mitigations for adopting the strategy
Next Steps	Potential next steps in continuing to develop and realizing the strategy
Summary	Summary of the strategy

Strategy for Digital Identities

General

Revisions to the document as a whole

Public Comments

All comments were reviewed, considered, may have been implemented even if not explicitly referenced during this meeting.

1. **Inconsistencies**: Several comments pointed out inconsistencies in language and concepts
   - **Response**: Fixed errors and consolidated language; defined some undefined terms to help clarify the narrative

Section Overview

Process: Development process; application of Guiding Principles; relevant national initiatives

Public Comments

2. **Insufficient input**: Social services perspective was underrepresented in Focus Group input
   - **Response**: Acknowledged that social services were not well represented; need to improve social service perspective as industry and DxF matures; relied some on public comment to fill some gaps

Strategy for Digital Identities… continued

Section Overview

Purpose: Purpose and use case for digital identities within the Data Exchange Framework

Public Comments

3. **Inconsistent use of language**: Confuses person resolution, patient matching, record linking concepts
   - **Response**: Clarified and defined terms; standardized terminology to "person matching" and "record linking" which were defined to include patient search and aggregation, respectively

4. **Inaccuracies may limit utility**: Lack of validation of digital identity attributes may negate utility of effort
   - **Response**: Added language that validation of attributes is beyond scope of digital identities so as to focus on person matching and record linking, noting that secondary uses of demographics in digital identities are beyond the Purpose

5. **Misrepresents AG input**: Some AG member input was inappropriately characterized as "AG recommendation"
   - **Response**: Reworded to focus on recommendations coming from Focus Groups with feedback from AG, DSA Subcommittee, and public comment

Strategy for Digital Identities… continued

Section Overview

Data Attributes: Data attributes comprising digital identities

Public Comments

6. **Demographics**: Supported as written *versus* Should add gender and/or race, ethnicity, preferred language and/or all USCDI demographics to align with national standards, improve matching, align with federal rules, or avoid vendors dropping support

- **Response**: Revised to include gender to align with nationally-recognized standards; retained exclusion of race, ethnicity, SOGI, preferred language as Focus Groups felt there was insufficient value for person matching, record linking to overcome consumer concerns, recognize exclusion of secondary uses, limit statewide data repository to minimum necessary for Purpose; added study results demonstrating little value in race, ethnicity

7. **Unique identifiers**: Supported inclusion of unique health-related identifiers; should only include social services identifiers after discussion and if agreed appropriate

- **Response**: Retained inclusion of unique identifiers limited to those related to health and social services delivery, added "if agreed appropriate" for social services identifiers

Note: Federal rules and DSA/P&P still require exchange of full USCDI; race, ethnicity, SOGI, and preferred language are not supported in nationally-recognized standards for person matching

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Strategy for Digital Identities… continued

Section Overview

Data Standards: Data standards for attributes comprising digital identities; introduction of tokenization

Public Comments

8. **USCDI v2**: Should standardize on USCDI v2, not USCDI v1
   - **Response**: Revised to USCDI v2 to align with DSA Data Elements to Be Exchanged and reduce confusion

9. **Clarify "address"**: Clarify if address attribute is limited to physical or mailing addresses; should include PO Box as valid address (especially for homeless)
   - **Response**: Clarified that physical, mailing, and PO Box addresses are allowed to align with US@ Project

10. **Technology, standards not enough**: Accurate identification is not just a technology problem; standards are insufficient if not adopted, improved, incentivized
    - **Response**: Acknowledged the need for education, communication, improved processes, incentives

11. **Support for tokenization**: Several commenters strongly supported tokenization; some suggesting that unique identifiers other than health- social services-related might be considered when tokenization is implemented

Strategy for Digital Identities… continued

Section Overview

Permitted Uses: Discussion of the permitted purposes to be embodied in the DSA / P&Ps

Public Comments

12. **Allow secondary uses**: Prohibition increases effort to obtain demographics; may limit valuable contributions to public good
    - **Response**: Retained restriction as aligned with Purpose of person matching, record linking and limit statewide data repository to minimum necessary for Purpose; added language that permitted purposes should be regularly reviewed

13. **Remove minimum necessary**: Restriction to minimum necessary should not apply to this Purpose as access to all attributes maximizes accuracy of a match (i.e., minimum is “all”)
    - **Response**: Removed minimum necessary requirement in Strategy as inappropriate for the stated purpose of person matching, record linking; ensured language not present in DSA

Note that Permitted Uses is most appropriate for a statewide person index

Strategy for Digital Identities… continued

Section Overview

Statewide Person Index: Discussion of potential creation of a statewide person index and related concepts

Public Comments

14.Support: Strong support for statewide person index; value in locating records as well as person matching and record linking

15. Does not acknowledge other initiatives: Should acknowledge role of state initiatives

- **Response**: Added language as suggested

16. Required participation: DxF Participants should be required to submit attributes to the statewide person index to improve digital identities; use of index could remain optional

- **Response**: Added that participation might be reviewed in future P&Ps through public, transparent process per P&P if the statewide person index is created

Strategy for Digital Identities… continued

Section Overview

Potential Burdens: Burdens and mitigations for adopting the strategy

Public Comments

17. Does not acknowledge other initiatives: Should acknowledge progress of HIOs; leverage HIO investment

- **Response**: Added language as suggested

Section Overview

Summary: Summary of the strategy

Public Comments

18. Difficult to understand: Strategy was difficult to discern when combined with discussion and other material

- **Response**: Replaced Summary at end of document with Executive Summary at beginning to summarize salient components in one place; added section on uses of digital identities; moved Permitted Purpose to after Statewide Person Index

Strategy for Digital Identities

More than 1/3 of all comments received were on the topics of
Attributes of a Digital Identity and Permitted Uses

Questions or Comments

Attributes

Thoughts or questions on data attributes to be included in digital identities?

Permitted Uses

Thoughts or questions on permitted purposes for attributes, perhaps limited to a statewide index?

General

Other thoughts or questions?

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Data Exchange Framework Implementation

Data Exchange Framework Implementation Overview

Data Exchange Framework Governance must balance the need to move quickly with the needs for transparency, ongoing and robust stakeholder engagement, and oversight.

July 1, 2022

- DxF will launch with CDII managing and overseeing all aspects of governance (e.g., publishing DSA P&Ps & developing DxF governance & programs).
- Current DxF Stakeholder Advisory Group and its DSA Subcommittee will sunset.
- New interim Implementation Advisory Committee and DSA P&P Subcommittee will be formed to support DxF implementation.
- CalHHS will develop a legislative proposal to establish a Health and Human Services Data Exchange Board.

2023

- CalHHS will establish the HHS Data Exchange Board to oversee implementation of the DxF.
- Governance functions will be divided between the HHS Data Exchange Board and CDII as shown on slide 64.
- Existing committees will be sunset and the Board and CalHHS will establish and charge new advisory committees and subcommittees.

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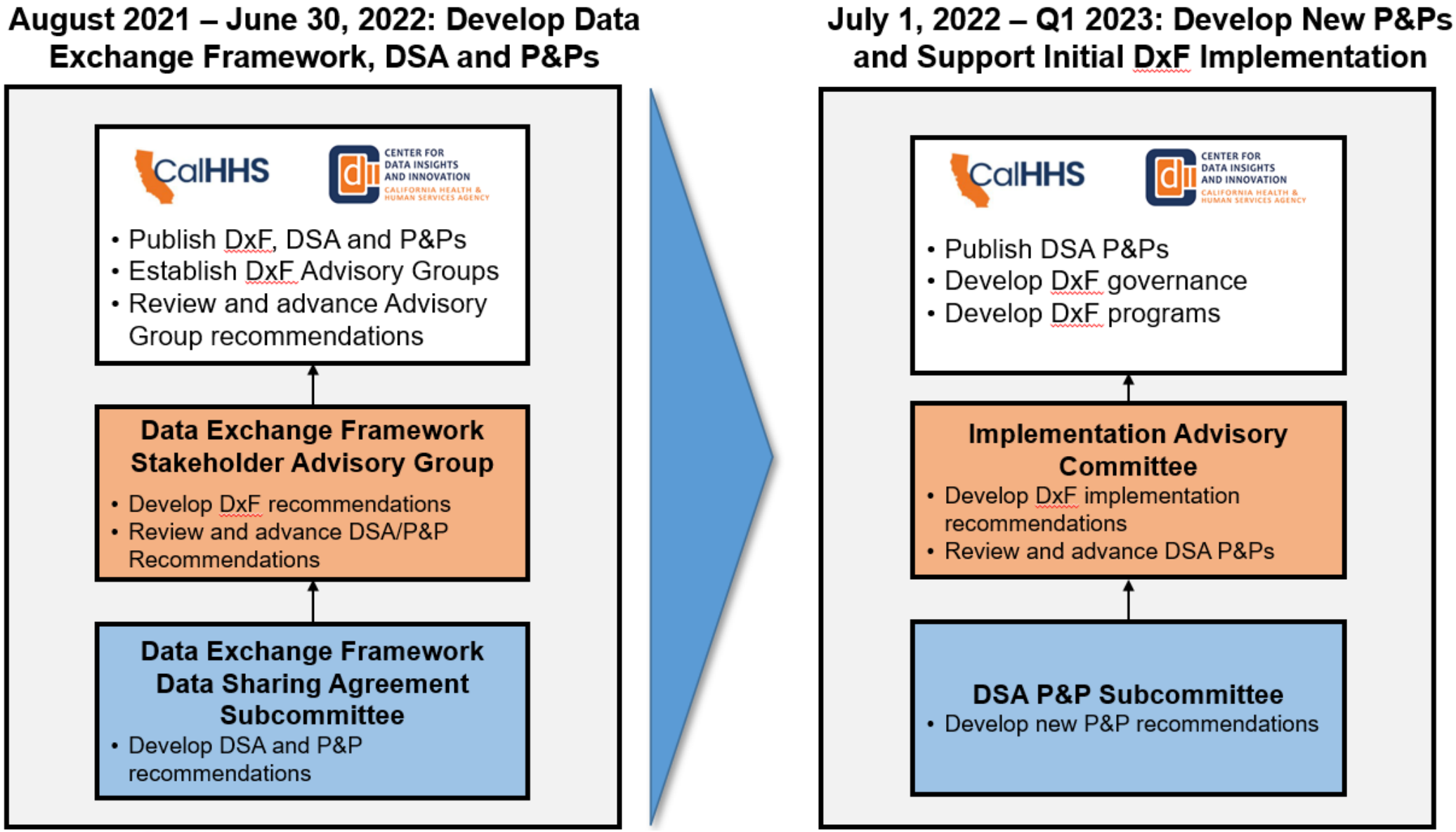
DxF Implementation August 2021 to Q1 2023



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↑ Flow of proposed recommendations

Interim Advisory Committees Overview

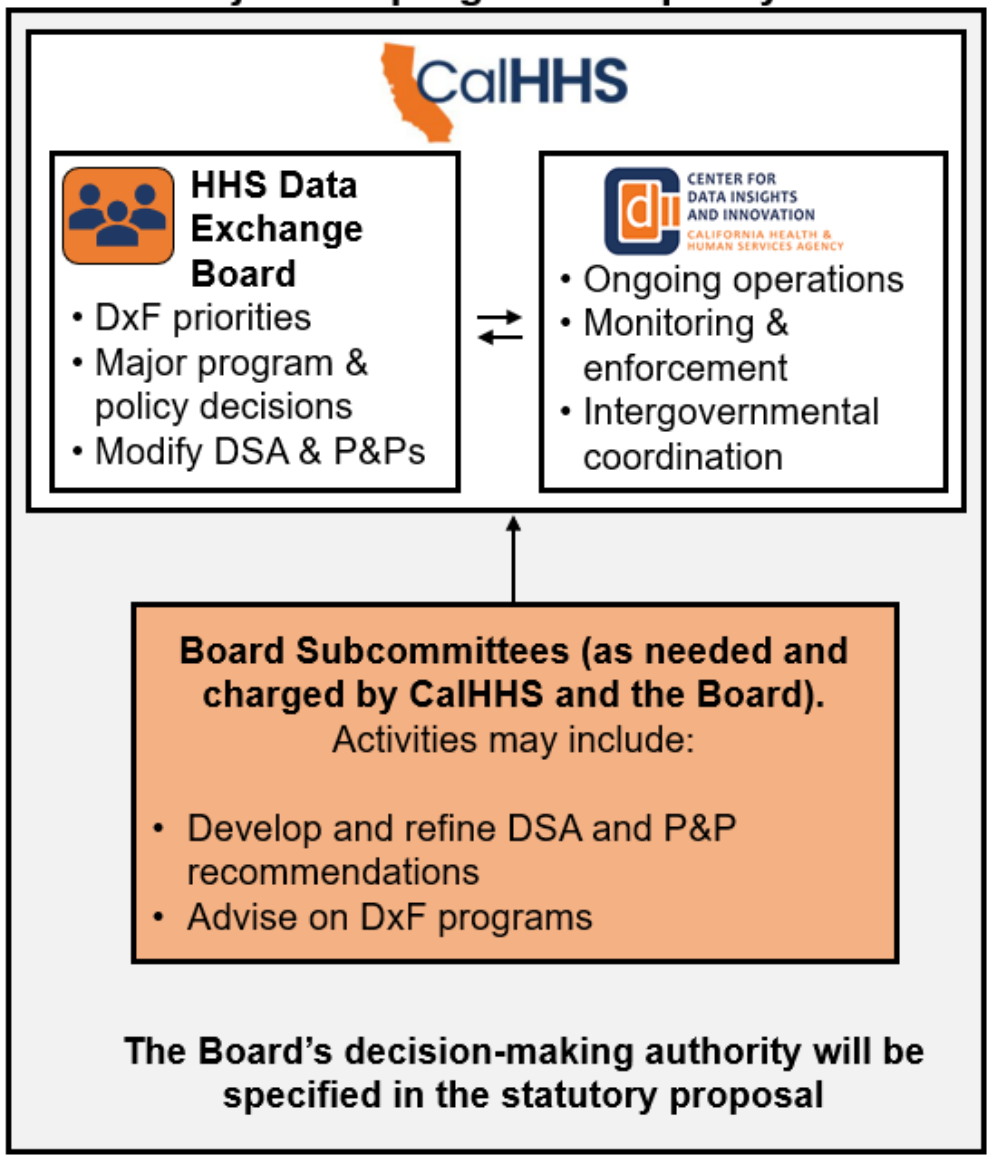
Between July 1, 2022 and Q1 2023, CDII will establish an interim Implementation Advisory Committee and DSA P&P Subcommittee (Advisory Committees)

Interim Advisory Committees

- **Charges and Authority**
  - Advisory Committees will operate under domain specific charges prescribed by CDII.
    - **The Implementation Advisory Committee** will review and advance DxF implementation recommendations to CDII for consideration.
    - **The DSA P&P Subcommittee** will review and advance DSA P&Ps to CDII for consideration.
  - Advisory Committees will not have decision-making authority.
- **Composition**
  - The Director of CDII or their designee will serve as the chair for both Advisory Committees.
  - Advisory Committees will be composed of representatives from consumer, CBO, provider, health system, and health plan representatives in addition to health IT and privacy and security professionals and others selected by the Director of CDII.
- **Operations**
  - Advisory Committees will meet on an approximately monthly basis or at a cadence determined by the Chair.
  - Advisory Committees will not be subject to the Bagley-Keene Open Meeting Act, but Advisory Committee meetings will be open to the public and meeting materials will be publicly posted.

DxF Implementation Q1 2023 and Beyond

Q1 2023+ Establish HHS Data Exchange Board to oversee major DxF program and policy decisions



HHS Data Exchange Board Composition & Qualifications

- The HHS Data Exchange Board will comprise seven voting members, including:
  - The Secretary of CalHHS or their designee (Chair and ex officio member);
  - Two individuals appointed by the Governor at least one of which will be a consumer representative;
  - One individual appointed by the Speaker of the California State Assembly;
  - One individual appointed by the by the California State Senate President pro Tempore; and
  - One representative from the California Public Employee Retirement System (CalPERS) and one representative from Covered California (ex officio members).
- Appointed members will serve up to two four-year terms, and terms will be staggered to preserve institutional knowledge.
- Board members must have expertise in HIE and administration of public and private health care and/or social service delivery systems.
- Appointing authorities will attempt to make appointments so that the Board's composition reflects a diversity of experience and the cultural, ethnic, and geographical diversity of the state.
- Board members will be subject to strict conflict of interest policies.

HHS Data Exchange Board Operations

- The HHS Data Exchange Board will meet at a cadence determined by the Chair.
- To ensure transparency, the Board will be subject to the Bagley-Keene Open Meeting Act.

Data Exchange Framework Governance Functions

The HHS Data Exchange Board will have decision-making authority for a set of oversight activities for several governance functions. CDII will be responsible for supporting all governance activities and functions and for providing staffing and administrative support for the HHS Data Exchange Board.

Data Exchange Framework Governance Functions	
HHS Data Exchange Board	**CDII**
The Board will have the authority to: • Modify the DxF Data Sharing Agreement • Establish New and Modify Existing Data Sharing Agreement Policies and Procedures • Develop Processes to Coordinate with CalHHS Departments and Use Their Authority to Establish New Data Sharing Requirements and Regulations • Monitor and Enforce Data Sharing Agreement Policies and Procedures • Establish Criteria and Procedures for Qualifying Health Information Exchange Organizations • Develop Policy Proposals to Harmonize State Law with Federal Law • Advance and Refine Data Exchange Framework Priorities • Receive and Accept Gifts, Grants, or Donations from Individuals, Associations, Private Foundations, or Corporations (*in compliance with conflict-of-interest provisions*)	CDII will be tasked with and have the authority to: • Review Federal Data Exchange Standards and Advance Proposals to Align DxF Standards • Implement Procedures to Monitor and Enforce Compliance with Data Sharing Agreement Policies and Procedures • Oversee Dispute Resolution and Grievance Processes • Implement and Manage Data Exchange Intermediaries Qualification Processes and Procedures • Conduct and Manage Data Exchange Framework Communications and Education Activities • Coordinate with Other Branches of State and Local Government and Private Institutions • Establish, Appoint, Facilitate and Manage Advisory Groups and Subcommittees • Advance Recommendations to and Respond to Directives from the HHS Data Exchange Board • Develop and Implement Financing Proposals for DxF Initiatives and Programs.

For Discussion: Is this the right division of responsibilities between the HHS Data Exchange Board and CDII?

Closing Remarks and Next Steps

Work Completed

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**
✓	Provide feedback on elements of **draft DxF and DSA**
✓	Review **updates to the draft DxF and DSA** based on submitted feedback

Next Steps

CalHHS will:

- Summarize and post meeting notes.
- Release final versions of the **DxF, DSA, and P&Ps on or before July 1st**.
- Release the final version of the **Strategy for Digital Identities on or before July 31st**.
- Draft the legislative proposal to establish the HHS Data Exchange Board.
- Continue DxF implementation, including convening the Implementation Advisory Committee and DSA P&P Subcommittee.

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Thank You!

Thank you for advancing data exchange to improve the health and well-being of Californians!

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