

**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting Summary (v1)
Tuesday, March 22, 2022, 12:00 p.m. to 2:30 p.m.**

Attendance

Data Sharing Agreement Subcommittee Members in attendance: Chair John Ohanian, William (Bill) Barcellona, Jenn Behrens, Michelle (Shelley) Brown, Louis Cretaro, Elaine Ekpo, Sanjay Jain, Diana Kaempfer-Tong, Elizabeth Killingsworth, Helen Kim, Carrie Kurtural, Steven Lane, Lisa Matsubara, Deven McGraw, Eric Raffin, Morgan Staines, Ryan Stewart, Lee Tien, Belinda Waltman, Terry Wilcox.

Data Sharing Agreement Subcommittee Staff and Presenters in attendance: Rim Cothren (HIE Consultant to CalHHS/CDII), Lammot du Pont (Manatt Health Strategies), Kevin McAvey (Manatt Health Strategies), Helen Pfister (Manatt Health), Elaine Scordakis (CalHHS/CalOHII), Nikhil Sethi (Manatt Health), Khoua Vang (CalHHS/CDII), Justin Yoo (Manatt Health Strategies).

Members of the Public in attendance: Approximately 46 public attendees joined this meeting via Zoom video conference or through call-in functionality.

Meeting Notes

Meeting notes elevate points made by presenters, Data Sharing Agreement Subcommittee Members, and public commenters during the Data Sharing Agreement Subcommittee meeting. Notes may be revised to reflect public comment received in advance of the next Data Sharing Agreement Subcommittee meeting. Meeting materials, full video recording, transcription, and public comments may be found at: <https://www.chhs.ca.gov/data-exchange-framework/>.

Welcome and Roll Call

John Ohanian, Chief Data Officer, California Health & Human Services (CalHHS), welcomed attendees to the fifth meeting of the Data Exchange Framework (DxF) Stakeholder Advisory Group Data Sharing Agreement (DSA) Subcommittee. DSA Subcommittee Members were named and introduced via roll call.

Meeting Objectives

John Ohanian read the DxF vision statement developed by CalHHS and the Stakeholder Advisory Group and shared the meeting objectives.

Open Meeting Act Requirements

John Ohanian stated that beginning April 1, 2022, public meetings supporting DxF development will transition to a primarily in-person meeting structure. As a result, the sixth and final meeting of the DSA Subcommittee on April 26th will take place in Sacramento, California. A quorum of over half the DSA Subcommittee members will be required to attend the DSA Subcommittee meeting in-person and members of the public will be able to attend the meeting in-person or via teleconference.

(Meeting information for the April 26th meeting will be made available on the CalHHS DxF website prior to the meeting: <https://www.chhs.ca.gov/data-exchange-framework/>.)

Data Exchange Framework (DxF) Governance

Lammot du Pont, Senior Advisor, Manatt Health Strategies, stated that the Stakeholder Advisory Group continues to discuss the structure of a potential governance model for the DxF and its DSA.

Du Pont noted the eleven proposed governance functions that were previously discussed by the Stakeholder Advisory Group and highlighted those with implications for the DxF DSA and its policies and procedures (P&Ps) including those that pertain to:

- creation and curation of the DxF DSA and P&Ps (#2, 3, 10);
- enforcement and monitoring (#5, 6); and
- identification and qualification of exchange intermediaries (#8).

Comments from DSA Subcommittee Members included:

- Proposed governance functions should explicitly acknowledge that the DxF DSA and its P&Ps will be modified, as needed, to maintain alignment with national data sharing initiatives.

Data Sharing Agreement (DSA) and Policies & Procedures Update

Rim Cothren, Independent HIE Consultant to CDII, stated that AB 133 requires the establishment of a single data sharing agreement and a common set of P&Ps by July 1, 2022. Cothren stated that a set of foundational P&Ps would be established by the legislative deadline, and that additional P&Ps would be developed over time. Cothren shared the list of five P&Ps that would be released by July 1, 2022 and the one P&P that is tentatively planned for release by the same date.

Cothren stated that proposed drafts for public comment of the DxF DSA and initial set of foundational P&Ps would be discussed with the DSA Subcommittee during the April 26th meeting and that full drafts would be released broadly for public comment in May 2022.

Digital Identity Strategy Update

Rim Cothren introduced statutory language that requires the development of a strategy for unique, secure digital identities and reviewed key definitions. Cothren then discussed emerging concepts of the strategy, originating from discussions at ongoing digital identities focus group meetings. Concepts included:

- The approach for digital identities should have a focus on linking data to the correct individual, as opposed to creating a ‘golden record’.
- Digital identities could include demographic data as described in USCDI v1 as well as unique identifiers.
- Existing relevant standards and guidelines include value sets in USCDI v1 but there is also a need for standards for elements that currently lack sufficient guidelines.
- A statewide master person index (MPI) could support coordination across the MPIs used by individual organizations.

Comments from DSA Subcommittee Members included:

- The approach for digital identities should leverage national strategies such as those being pursued by the CARIN Alliance and DaVinci.
- It is unclear what is the benchmark by which a digital identity will be considered to be ‘unique’ or ‘secure’.

Privacy Requirements

Cothren asked how the DxF DSA should address the issue of privacy and permissible uses of digital identities.

Comments from DSA Subcommittee Members included:

- The approach for ensuring privacy of digital identities should
 - consider options for user authentication
 - focus on identifying applicable scenarios and use cases
 - address issues pertaining to consents and opt-in and opt-out
 - align with the approaches of related initiatives including California’s Health Care Payments Data Program.
- There should be guardrails and policies to prevent misuse of digital identities.
 - Digital identities could identify a list of appropriate uses which may include uses pertaining to patient care.
 - There are ‘gray areas’ between legitimate and illegitimate uses of digital identities that should be expounded upon.
- Some unique identifiers that may be part of a digital identity have restrictions on the ways in which they can be used (e.g., Medi-Cal ID).
- There are patchworks of privacy and security law depending on the entity involved (e.g., government vs. non-government), particularly as it pertains to public health uses.
- A statewide MPI that coordinates identity across contexts could be helpful.
- Some individuals may not have associated identifiers that may be included in a digital identity (e.g., phone number, address).
- Manual effort may be needed to address some matching issues.
- Provisions of the DSA and P&Ps pertaining to digital identities should be shared with county counsel associations to ensure alignment and support implementation.

Security Requirements

Cothren asked if security requirements for digital identities should differ from those for protected health information and whether language on security in the DxF DSA or P&Ps should include special treatment of digital identities.

Comments from DSA Subcommittee Members included:

- Digital identity data should be protected to at least the same level as health data.

Public Comment

Rim Cothren opened the meeting for spoken public comment, which included:

- Jonathon Feit, representative for the California Fire Chiefs Association, who recommended that the digital identities strategy consider how data will be linked to individuals who face particular barriers to accurate linkage (e.g., those whose demographic information may be stored inconsistently across systems, those needing care in emergency or triage environments).
- Jerry Hall, who recommended that the DxF and its DSA include safeguards against potential misuse of individuals' data, including line-level control of data access permissions and transparency with regard to which entities have access to the data governed by the DxF and its DSA.

DxF DSA Content: Third Set of Topics

Rim Cothren introduced concepts and draft language for the third set of DxF DSA topics which included:

1. Qualified Network
2. Uses and Disclosures
3. Minimum Necessary

The document with draft language is available at <https://www.chhs.ca.gov/data-exchange-framework/>.

Qualified Network

Cothren introduced the concept of a qualified network or other intermediary.

Comments from DSA Subcommittee Members included:

- The concept of a qualifying intermediary should be included as a part of the DxF and its DSA and P&Ps.
- The approach for qualifying intermediaries could focus on qualifying the intermediary itself or the underlying technologies.
 - Qualifying intermediaries may be less burdensome than qualifying technologies.
- Required signatories of the DxF DSA should be provided a list of qualifying intermediaries that would be able to meet DxF DSA requirements on behalf of the required signatory.

- Intermediaries could be asked to revise their own participation agreements to be compatible with the DxF DSA in order to achieve qualified status.
- Developing the infrastructure for the initial and ongoing qualification process may be resource-intensive.
- The DxF DSA intermediary qualification approach could leverage or accept 'qualified' status as determined by other qualification approaches as being sufficient to be considered qualified for the purposes of the DxF DSA, potentially reducing the amount of new review and required resources.
- Required signatories of the DxF DSA that choose to use a qualifying intermediary may not have to sign the DxF DSA if all requirements are met by the intermediary.
- Intermediaries may not need to be signatories to the DSA
 - if the primary goal in having intermediaries sign is to enable the qualification process, which can be accomplished using alternative methods and instruments.
 - if the approach includes required flow downs from the signatory to their intermediary.
- The criteria that determines 'qualified' status will need to be carefully considered.
- The structure of the qualification process will help determine answers to operational questions including whether intermediaries need to be party to the DxF DSA.
- The approach for qualifying intermediaries should be accessible to small, rural, and other under-resourced organizations.

Uses and Disclosures

Cothren introduced the concept of uses and disclosures.

Comments from DSA Subcommittee Members included:

- Allowing all uses and disclosures consistent with applicable law is a relatively permissive approach.
- Some members expressed support for [draft section 11.2](#) while others thought it was too broad.
- There may be a potential conflict between [draft sections 11.2 and 11.4](#) with regard to the level of restrictions that are described.
- Narrowing the range of permissible uses and disclosures will require data recipients having to silo and treat differently data received under the DxF DSA from other exchanged information.
- Language in the DxF DSA should clarify the meaning of the term 'own benefit'.
- The DxF DSA should address the issue of downstream control of data; limited ability to control downstream uses may limit willingness among participants to exchange data.
- The DxF DSA could clearly state prohibited uses of data to build trust among exchange partners.

- The DxF DSA could allow uses and disclosures to the extent permitted by law and as allowed under each entity's own privacy practices.

Minimum Necessary

Cothren introduced the concept of minimum necessary.

Comments from DSA Subcommittee Members included:

- Draft language for the minimum necessary concept appears consistent with similar language in other agreements.
- Exchange of the minimum necessary may be operationally challenging due to technological limitations.
- DxF DSA language could include a clause stating that data will be shared to the extent technologically feasible.
- It should be made clear that participants may not use a 'to the extent technologically feasible' clause as a reason to avoid advancing technological investments and infrastructure.
- The data requestor should be responsible for requesting the minimum necessary in a query-based exchange.

Next Steps and Closing Remarks

John Ohanian thanked DSA Subcommittee Members and the public for their engagement. Ohanian reviewed project next steps and noted that the next meeting will take place in a primarily in-person meeting format on April 26th, 2022. More information about the next meeting is available at: <https://www.chhs.ca.gov/data-exchange-framework/>).

Appendix 1. Data Exchange Framework Data Sharing Subcommittee Members - Meeting Attendance (March 22, 2022)

Last Name	First Name	Title	Organization	Present
Ohanian	John	Chief Data Officer (Chair)	CalHHS	Yes
Atreja	Ashish	CIO and Chief Digital Health Officer	UC Davis Health	No
Barcellona	William (Bill)	Executive Vice President for Government Affairs	America's Physician Groups (APG)	Yes
Behrens	Jenn	Chief Information Security Officer	LANES	Yes
Brown	Michelle (Shelley)	Attorney	Private Practice	Yes
Cretaro	Louis	Lead County Consultant	County Welfare Directors Association of California	Yes
Ekpo	Elaine	Attorney	CA Dept. of State Hospitals	Yes
Jain	Sanjay	Sr. Business Analyst	Health Net	Yes
Kaempfer-Tong	Diana	Attorney	CA Dept. of Public Health	Yes
Killingsworth	Elizabeth	General Counsel & Chief Privacy Officer	Manifest Medex	Yes
Kim	Helen	Senior Counsel	Kaiser Permanente	Yes
Kurlej	Patrick	Director, Electronic Medical Records & Health Information Exchange	Health Net	In Memoriam
Kurtural	Carrie	Attorney & Privacy Officer	CA Dept. of Developmental Services	Yes
Lane	Steven	Clinical Informatics Director Family Physician	Sutter Health Palo Alto Medical Foundation	Yes
Matsubara	Lisa	General Counsel & VP of Policy	Planned Parenthood Affiliates of California	Yes
McGraw	Deven	Lead, Data Stewardship and Data Sharing, Ciitizen Platform	Invitae	Yes

Last Name	First Name	Title	Organization	Present
Raffin	Eric	Chief Information Officer	San Francisco Department of Health	Yes
Staines	Morgan	Privacy Officer & Asst. Chief Counsel	CA Dept. of Health Care Services	Yes
Stewart	Ryan	System VP, Data Interoperability and Compliance	CommonSpirit Health	Yes
Tien	Lee	Legislative Director and Adams Chair for Internet Rights	Electronic Frontier Foundation	Yes
Waltman	Belinda	Acting Director, Whole Person Care LA	Los Angeles County Department of Health Services	Yes
Wilcox	Terry	Director of Health Information Technology/Privacy & Security Officer	Health Center Partners	Yes