California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting Summary (v1)
Wednesday, December 22, 2021, 11:00 a.m. to 1:30 p.m.

Attendance

Data Sharing Agreement Subcommittee Members in attendance: Chair John Ohanian, William (Bill) Barcellona, Jenn Behrens, Michelle (Shelley) Brown, Louis Cretaro, Elizabeth Killingsworth, Helen Kim, Patrick Kurlej, Carrie Kurtural, Steven Lane, Lisa Matsubara, Deven McGraw, Eric Raffin, Morgan Staines, Lee Tien, Belinda Waltman.

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

Members of the Public in attendance: Approximately 34 public attendees joined this meeting via Zoom video conference or through call-in functionality.

Meeting Notes

Meeting notes elevate points made by presenters, the 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) and Chair of the Data Sharing Agreement (DSA) Subcommittee welcomed attendees to the second meeting of the Data Exchange Framework (DxF) Stakeholder Advisory Group 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.

Public Comment

John Ohanian opened the meeting for spoken public comment. There were no spoken public comments given. (For written public comment submitted through the Zoom interface, see the Q&A log at https://www.chhs.ca.gov/data-exchange-framework/#december-22-2021).

Data Sharing Agreement (DSA) Subcommittee Charter

John Ohanian stated that the DSA Subcommittee Charter had been revised to incorporate feedback received at the DSA Subcommittee's November meeting. Ohanian reviewed revisions to the Charter and noted that the updated Charter, in both tracked-change and non-tracked change versions, was available on the public website: https://www.chhs.ca.gov/data-exchange-framework/#november-8-2021.

Data Exchange Framework (DxF) Guiding Principles & the DxF DSA

John Ohanian introduced the DxF Guiding Principles developed by CalHHS and the Stakeholder Advisory Group. Ohanian noted that these Principles were still in draft form and would be finalized in the coming weeks. Ohanian stated that the Principles should be considered as guidance from the Stakeholder Advisory Group and that it was the responsibility of the DSA Subcommittee to consider the Principles in its deliberations and incorporate them in its outputs.

General comments from DSA Subcommittee Members included:
- Consider whether the Principles should focus on data exchange or if they should also address issues that are relevant to and supportive of data collection, curation, and use.
- Include references to individuals' proxies and caregivers, as appropriate.
- Provide additional language regarding data security and privacy.

Recommendations pertaining to specific Principles included:
- For Principle 1, Advance Health Equity, clarify whether the term 'disproportionate gaps' refers to gaps in data and/or gaps in outcomes that disproportionately impact particular groups.
- For Principle 3, Support Whole Person Care, include language regarding the support for an individual's care coordination.
- For Principle 4, Promote Individual Data Access, address the privacy rights of minors and others who may not want caregivers or others to access certain sensitive health information.
- For Principle 7, Adhere to Data Exchange Standards, include references to international standards as applicable.

Key Considerations for the DxF DSA

Rim Cothren, Health Information Exchange (HIE) Consultant to CalHHS CDII, introduced key considerations and operating assumptions that would inform the

development of the DxF DSA across the topics of: (1) technology; (2) the role of scenarios; and (3) exchange modalities.

Technology
Cothren stated that the DxF DSA will be technology agnostic and accommodate both peer-to-peer arrangements and exchange arrangements using an intermediary.

Comments from DSA Subcommittee Members included:
- General support for the approach to accommodate both peer-to-peer arrangements and arrangements using an intermediary.
- The DxF DSA should accommodate, but not require, the use of an intermediary for a given data type or exchange purpose.
- While the DxF DSA may be agnostic with regard to the technology used to exchange data, it should encourage standardization of data structure and vocabulary.
- It may be helpful to provide signatories with a suggested implementation approach or best practices to support robust data exchange.
- As a means to leverage existing infrastructure and data sharing agreements, an entity's participation in a network that meets certain specific criteria could be considered as having satisfied applicable DxF DSA requirements.

Role of Scenarios
Cothren stated that the six data exchange scenarios identified by the Stakeholder Advisory Group will serve as a "floor" for the scope of the DxF DSA. The document describing the six scenarios is available at: https://www.chhs.ca.gov/wp-content/uploads/2021/10/Data-Exchange-Framework-Pre-Read-Materials. Cothren stated that the DxF DSA must support all six scenarios at a minimum, but that it may also address other scenarios not explicitly called for by the Stakeholder Advisory Group.

Comments from DSA Subcommittee Members included:
- The scenarios should include a more explicit focus on individual access to data.
- The DxF DSA should address issues of reciprocity and bidirectionality within each of the supported scenarios; for example, how data provided to public health departments gets shared with community providers.

Exchange Modalities

Cothren stated that the DxF DSA must support ALL the exchange modalities prompted by the scenarios which may include query-based exchange; message delivery; publish-subscribe arrangements; and bulk data exchange.

Comments from DSA Subcommittee Members included:
- The DxF DSA should support exchange modalities beyond those listed to include exchange of customized datasets and view-only access.

- The use of standards like Fast Healthcare Interoperability Resources (FHIR) should be addressed as part of the supported exchange modalities.
- Support for a wide variety of exchange modalities heightens the need for a robust system of governance and accountability.

Threshold Questions for the DxF DSA

Jennifer Schwartz, Chief Counsel, CalHHS CDII introduced threshold questions for discussion across the topics of: (1) definitions, exchange purposes, and permitted uses; (2) DxF DSA signatories; and (3) addressing differing levels of technical readiness to exchange.

Definitions, Exchange Purposes and Permitted Uses

Schwartz introduced the legislative language describing required exchange purposes. Schwartz asked Subcommittee Members for their thoughts on appropriate definitions for each of the required exchange purposes and for the potential additional non-mandated purposes.

Comments from DSA Subcommittee Members included:
- General
  - The DSA Subcommittee should consider which exchange purposes and sub-purposes are required and which are permitted.
  - The DxF DSA should only identify required exchange purposes. With respect to permitted purposes, the DxF DSA should not attempt to enumerate every potential permitted purpose, but instead should allow for exchange for any purposes allowed by law.
  - Identification of required purposes should take into consideration the experiences of other data exchanges, many of which discovered that if an exchange purpose is not explicitly required, the exchange of data for the non-required purpose does not occur.
  - The DxF DSA and its definitions should align with applicable federal laws (e.g., the Health Insurance Portability and Accountability Act, HIPAA) and California state laws (e.g., the Confidentiality of Medical Information Act).
- Treatment
  - The DxF DSA should clearly define treatment, a term that is used differently by various sectors.
  - Care coordination is one aspect of care provision that can be considered to be treatment or operations depending on the entity involved.
  - The HIPAA definition of treatment may not adequately encompass services provided by social service organizations and their relevant data.
  - While the treatment exchange purpose is generally more familiar to health care entities than other exchange purposes, it still requires consideration of a number of complexities such as intersections with patient consent and privacy.

- Payment
  - Existing and forthcoming data exchange frameworks vary in how they define the payment exchange purpose but often pose additional limitations to exchange. For example, the draft Trusted Exchange Framework and Common Agreement (TEFCA) limits the payment exchange purpose to utilization review.
  - The definition of the payment exchange purpose should leverage existing definitions with modifications or separate guidance as necessary to address identified gaps.
  - Defining payment to appropriately include social services activities may be a challenge given differences in the entities receiving payment, sources of funds, and applicability of HIPAA.
- Operations
  - Operations is a broad exchange purpose that can include a wide variety of activities from quality assessment, to training, to fundraising.
  - An overly broad definition of operations may hamper trust and raise compliance costs among participants.
  - General support for limiting the operations exchange purpose to a more narrowly defined set of sub-purposes.
  - Care coordination and quality assessment are specific sub-purposes that should be included in the DxF DSA.
- Public Health
  - The DxF DSA may provide an opportunity to build individuals' trust in the appropriate stewardship of public health data by health care entities.
  - Modernization and standardization of technological systems used by public health jurisdictions would support improved public health data exchange and use.
- Other Exchange Purposes
  - General support for including the benefits determination activity of state and local governments, nonprofits, and other contracted entities as a permitted exchange purpose.
  - It may be challenging to achieve robust security and privacy practices for county-involved exchange purposes given existing variation in technological practices across the state.
  - Robust participation of social service organizations in data exchange may require counties to migrate some of their social service units under the auspices of their health care units and participate in business associate agreements.
  - The DxF DSA should clarify what forms of research may be permitted under a research exchange purpose e.g., IRB-approved research vs. less formalized forms of research.
  - The DxF DSA should ensure that individuals and their proxies have appropriate access to their own health information and include guardrails to maintain privacy, security, and patient trust.

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DxF DSA Signatories
Given the short timeline for the development of the DxF DSA, Schwartz proposed that it be developed with a focus on the mandated signatories. However, the DxF DSA should also provide a trust framework that other organization types could be comfortable signing.

Comments from DSA Subcommittee Members included:
- General support for the proposed approach to focus on mandated entities, but also establish a pathway for non-mandated organizations (particularly community-based organizations) to sign the DxF DSA.
- The DxF DSA should include provisions that are supportive of robust participation in data exchange such as a requirement that entities must share data in order to access data governed by the agreement.
- The DxF DSA can provide potential non-mandated signatories with additional support to onboard to the DxF DSA such as offering a readiness assessment and a phased-approach to onboarding.

Addressing Differing Levels of Technical Readiness to Exchange
Schwartz asked the Subcommittee for input on how to balance the goal of using the DxF DSA to meaningfully improve data exchange with the goal of including all required signatories, including those with differing levels of technological capabilities and readiness.

Comments from DSA Subcommittee Members included:
- Community-based organizations and other potential non-mandated signatories face technological challenges in participating in robust data exchange.
- There are a number of affordable and readily available technological solutions that under-resourced organizations can use to participate in exchange.
- Having the DxF DSA accommodate entities', particularly community-based organizations', use of tools to view data would be an important step in advancing social service data exchange in the state. However, if the DxF DSA requires bidirectional exchange, it may deter community-based organizations from signing on to the DxF DSA at all.
- Additional resources, including financial incentives, may help resource-limited organizations onboard to the DxF DSA.

Developing the DxF DSA
Jennifer Schwartz discussed the differing purposes and proposed roles of the DxF, DxF DSA, and supporting policies and procedures.

Comments from DSA Subcommittee Members included:
- General support for the proposed purposes and roles of the DxF, DxF DSA, and policies and procedures.

Schwartz and Lammot du Pont, Senior Advisor, Manatt Health Strategies, shared the approach and timeline for collecting and incorporating feedback from the DSA Subcommittee Members and other stakeholders into the DxF DSA. Schwartz noted that the Stakeholder Advisory Group and the DSA Subcommittee will address a number of topics pertaining to the development of the DxF, DxF DSA, and policies and procedures in the coming months including: an overarching governance approach, processes for amendments or revisions, and enforcement.

Closing Remarks

John Ohanian thanked DSA Subcommittee Members and the public for their engagement. Ohanian reviewed project next steps and the dates for the remaining DSA Subcommittee meetings through April 2022. Ohanian noted that the next meeting will take place on January 18, 2022.

Appendix 1. Data Exchange Framework Data Sharing Subcommittee Members - Meeting Attendance (December 22, 2021)

Last Name	First Name	Title	Organization	Present
Ohanian	John	Chief Data Officer (Chair)	California Health & Human Services Agency	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
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	Yes
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
Raffin	Eric	Chief Information Officer	San Francisco Department of Health	No
Staines	Morgan	Privacy Officer & Asst. Chief Counsel	CA Dept. of Health Care Services	Yes

Last Name	First Name	Title	Organization	Present
Stewart	Ryan	System VP, Data Interoperability and Compliance	CommonSpirit Health	No
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	No

* Michael Marchant attended the December 22nd meeting as a public participant on behalf of Dr. Ashish Atreja.