

**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting Summary (v1)
Thursday, November 8, 2021, 11:00 a.m. to 1:00 p.m.**

Attendance

Data Sharing Agreement Subcommittee Members in attendance: Chair John Ohanian, Ashish Atreja, 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, 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), Jonah Frohlich (Manatt Health Strategies), Courtney Hansen (CalHHS/CDII), Kevin McAvey (Manatt Health Strategies), Jennifer Schwartz (CalHHS/CDII), Elaine Scordakis (CalHHS/CalOHII).

Members of the Public in attendance: Approximately 23 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 Introductions

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

Vision and Meeting Objectives

John Ohanian read the DxF vision statement developed by CalHHS and the Stakeholder Advisory Group. He then introduced the purpose of the Subcommittee as supporting the development of a single data sharing agreement, i.e., the DxF DSA, that all applicable entities and organizations must execute prior to January 31, 2023. Ohanian described the envisioned future state which would build on and bolster

systems and processes that are working well and lay the foundation for a robust data exchange that will improve the health of all Californians.

Public Comment

John Ohanian opened the meeting to provide opportunity 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/#november-8-2021>).

AB133 and Data Sharing Agreement Requirements

Courtney Hansen, Assistant Chief Counsel, CalHHS Center for Data Insights and Innovation (CDII), introduced herself and Jennifer Schwartz, Chief Counsel, CalHHS CDII. Hansen and Schwartz will develop the initial drafts of the DxF DSA based on recommendations from the Stakeholder Advisory Group and the DSA Subcommittee. Hansen noted that she will be going on maternity leave shortly and will be returning in the spring of 2022.

Hansen shared the scope and intended purpose of the DxF DSA as described in Assembly Bill (AB) 133. Hansen shared the list of applicable entities that would be required to execute the DxF DSA, the required timing for execution, and definitions for the health information that would be governed by the DxF DSA. Hansen emphasized that the DxF and the DxF DSA will be technology agnostic and noted that the DSA Subcommittee would also consider whether and how social services information can be included in the DxF DSA. As part of its work, Hansen noted that the DSA Subcommittee would provide recommendations regarding the optimal location of topics in the DxF DSA versus supporting policy and procedure documents.

Subcommittee Charge, Charter, and Workplan

Jennifer Schwartz stated that the purpose of the DSA Subcommittee is to support the Stakeholder Advisory Group in the development of recommendations for the creation of the DxF DSA as required by AB 133. The DSA Subcommittee will inform the development of the DxF DSA, review drafts and associated public comment, and advance recommendations to the Stakeholder Advisory Group. Schwartz noted that the DSA Subcommittee serves an important advisory role and does not have decision-making authority. Schwartz shared expectations of Members, including participation in DSA Subcommittee meetings which will take place approximately monthly through mid-2022. Schwartz expressed gratitude for the participation of DSA Subcommittee Members and asked the group to work together to develop a single statewide data sharing agreement and to support improved health information exchange in California.

DSA Subcommittee Member feedback on the Subcommittee's charge and charter included:

- The DSA Subcommittee should leverage existing DSAs when possible and reference them as appropriate. Doing so would reduce redundancy and the level of resources required to develop and maintain the DxF DSA.

- The DSA Subcommittee should assess limitations of existing data sharing agreements, particularly in the context of AB 133 requirements, and ensure that the DxF DSA addresses the identified limitations.
- The DSA Subcommittee should review and consider standards for topics and data types, e.g., social determinants data, that may be not be included in existing data sharing agreements.
- Detailed technical specifications and standards should not be specified in the DxF DSA. However, the DxF DSA must address technical considerations in sufficient detail to provide context and guidance for the requirements.

Specific suggestions and comments on the Charter included:

- Add additional text stating that the DxF DSA will leverage existing DSAs and will not be duplicative.
- Add the clause 'including but not limited to' when listing DSA Subcommittee activities or documents that may be reviewed.
- Add clarifying language on the extent to which technical specifications and standards will be included in the DxF DSA versus other supporting documentation.

Schwartz requested that DSA Subcommittee Members indicate whether they recommend approval of the Charter with the amendments discussed above. There was general consensus from the DSA Subcommittee that the Charter appropriately reflected the group's charge and responsibilities with the discussed amendments. Schwartz noted that a revised Charter would be shared in advance of the next meeting.

Overview of Existing Data Sharing Agreements

Rim Cothren, Health Information Exchange (HIE) Consultant to CalHHS CDII, provided an overview of five existing and emerging data sharing agreements, highlighting similarities and differences in purpose, governance model, typical participants, included components, and potential limitations. The five data sharing agreements and frameworks discussed were:

1. California Trusted Exchange (CTEN) CalDURSA
2. Carequality Connected Agreement
3. eHealth Exchange Data Use and Reciprocal Support Agreement (DURSA)
4. Model Modular Participants Agreement (MMPA)
5. Trusted Exchange Framework Common Agreement (TEFCA)

California Data Sharing Agreement: Basis for the Agreement and Core Content

Jennifer Schwartz asked the DSA Subcommittee to consider four key questions that would inform development of the DxF DSA:

1. What challenges is the DxF DSA trying to solve?
2. What are the challenges to creating the DxF DSA?
3. Which existing/emerging frameworks could serve as models?

4. What should the DxF DSA include?

What challenges is the DxF DSA trying to solve?

Jennifer Schwartz introduced challenges to data exchange in California which include, but are not limited to, fragmented, regionalized, and inconsistent data exchange across California; lack of full participation among stakeholders; unavailability of important data types; confusion about mental health, developmental disabilities, and substance use disorder data; and legal complexity of data sharing.

Comments from DSA Subcommittee Members included:

- Aligning stakeholders on common technical standards will be a significant challenge.
- The DSA Subcommittee should identify priority use cases and the minimum level of data exchange that organizations will be required to participate in.
- Organizations have differing approaches to sharing data for treatment versus data for payment, operations, and public health purposes.
- To improve data exchange, regulations or processes should expand the stakeholders required to exchange data and the types of data that are required to be exchanged.
- There should be policies to encourage and enforce adoption and the use of the DxF DSA.
- Successful implementation of the DxF DSA will require that sufficient training and implementation resources are available, particularly to small and/or under-resourced organizations.
- The DSA Subcommittee should consider the utility of the implementer construct, in which organizations with the necessary resources and technical infrastructure serve as the direct signatory of a data sharing agreement and act as a hub for and supporter of smaller or less-resourced organizations that participate in their networks.
- The DxF DSA should include provisions to address patient requests for their record and prioritize privacy and security.
- Some challenges, such as issues with the quality of data being exchanged, may not be fully solved by the DxF DSA.

What are the challenges to creating the DxF DSA?

Jennifer Schwartz introduced challenges to creating the DxF DSA which include, but are not limited to, an ambitious timeline and the need to create a document that is executable by all of the diverse applicable entities described in the statute.

Which existing/emerging frameworks could serve as models?

Lammot du Pont, Senior Advisor, Manatt Health Strategies, and Courtney Hansen shared the results of a pre-meeting survey that DSA Subcommittee Members completed. Results showed that DSA Subcommittee Members were most familiar with the CTEN CalDURSA followed by the Carequality Connected Agreement. Although

there was no consensus on an existing or emerging data sharing agreement that met all of the AB 133 requirements, DSA Subcommittee Members were most supportive of using the Carequality Connected Agreement as a model framework, followed by TEFCA and the eHealth Exchange DURSA.

Comments from DSA Subcommittee Members included:

- Existing and emerging DSAs have a variety of strengths and limitations based on characteristics such as frequency of updates; ease of onboarding; scope; inclusion of specific types of participants such as government partners; compatibility with California-specific context and law; and types of supported data exchange.
- Decisions about data exchange modalities and the types of organizations that are expected to be signatories will help determine which existing and emerging data sharing agreements may be appropriate models for the DxF DSA.
- The DxF DSA should draw on the strengths of various existing and emerging DSAs.
- Creating a DxF DSA that is simple and easy to understand will be a challenge.

What should the DxF DSA include?

Jennifer Schwartz shared results from the pre-meeting survey that asked DSA Subcommittee Members to select the topics and concepts that should be included in the DxF DSA.

Comments from DSA Subcommittee Members included:

- General support for a number of topics and concepts including, but not limited to: privacy and security, requirement to respond or reciprocity, and cooperation and non-discrimination.
- The DxF DSA may not need to address certain topics (e.g., breach notifications) if it references applicable law or existing data sharing agreements that address the topic.
- Some topics (e.g., references to data standards) should be placed in policy and procedure documents so that changes or modifications to standards and specifications don't require modifications or updates to the DxF DSA.
- Some topics (e.g., benefits of participation) are usually not within the scope of a data sharing agreement.

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 mid-December.

Appendix 1. Data Exchange Framework Data Sharing Subcommittee Members - Meeting Attendance (November 8, 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	Yes
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	Yes
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	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