



**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, February 23, 2022, 11:00 a.m. to 1:30 p.m.**

Attendance

Data Sharing Agreement Subcommittee Members in attendance: Chair Jennifer Schwartz, 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, 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), Kevin McAvey (Manatt Health Strategies), Elaine Scordakis (CalHHS/CalOHII), Khoua Vang (CalHHS/CDII), Justin Yoo (Manatt Health Strategies).

Members of the Public in attendance: Approximately 32 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

Jennifer Schwartz, Chief Counsel, California Health & Human Services (CalHHS) Center for Data Insights and Innovation (CDII), welcomed attendees to the fourth 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

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

Public Comment

Jennifer Schwartz opened the meeting for spoken public comment. There were no public comments given.

Data Exchange Framework (DxF) Data Sharing Agreement (DSA) Development Update

Jennifer Schwartz stated that AB 133 requires the establishment of a single data sharing agreement and a common set of policies and procedures (P&Ps) by July 1, 2022. Schwartz 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.

Schwartz stated that CalHHS would continue to solicit input from the Stakeholder Advisory Group, DSA Subcommittee, and other stakeholders on the DxF DSA and the P&Ps over the coming months. Schwartz asked DSA Subcommittee Members to provide written feedback on draft DxF DSA language after meetings and shared that full drafts of the DxF DSA and P&Ps would be released for public comment in May 2022.

Threshold Questions for the DxF DSA

Jennifer Schwartz introduced four threshold questions for the development of the DxF DSA on the topics of:

1. Data Quality
2. Uses and Disclosures
3. Specially Protected Information
4. Minimum Necessary

Data Quality

Schwartz discussed considerations for including provisions pertaining to data quality in the DxF DSA.

Comments from DSA Subcommittee Members included:

- Development of data quality requirements would first require a common definition of data quality which may encompass concepts of usability, availability, and integrity (i.e., accuracy, validity, precision, etc.).
- Most data sharing agreements allow data governed by the agreement to be exchanged in an 'as is' state.
- The DxF DSA should reference national processes and standards that support high data quality, aligning with broader efforts and reducing potential duplication of effort. Examples of initiatives developing such processes and standards include those led by the Sequoia Project and eHealth Exchange, and Project US@ for demographic data.
- The DxF DSA could establish a floor for data quality by, for example, including language prohibiting the intentional sharing of inaccurate data, requiring data be transmitted essentially unaltered from the source system, or encouraging exchange of structured data.

- Details for data quality should be included in the P&Ps and not in the DxF DSA.
- Data transmitters should have the primary responsibility for data quality, and the standards should be stricter depending on the data types and organizational types. Data quality standards should be stricter for government or health care entities and less strict for community-based organizations.
- Data quality requirements should be reasonable so as to allow all participants, including small or under-resourced providers and community organizations, to be able to comply.
- Concerns about data quality may be alleviated if data are transmitted with information about provenance so that data recipients may consider the context before using that data for specific purposes.
- There may need to be accountability processes to address cases where issues with data quality may cause harm to individuals receiving care.
- Development of any data quality provisions should be rooted in a strong understanding of the current state of data quality issues and their implications.

Uses and Disclosures

Schwartz asked to what extent participants should be able to retain, use, re-use, and/or repurpose data received through the DxF.

Comments from DSA Subcommittee Members included:

- Uses and disclosures could be limited to a set of specifically permitted purposes in order to build trust. The set of supported purposes could be expanded over time as trust is built.
- Alternatively, the DxF DSA could require that data obtained under the agreement be used in general compliance with applicable law.
- Provisions pertaining to uses and disclosures should be based on a principle of trust and respect for individual privacy.
- Limitations on uses and disclosures may be difficult to implement, as they require participants to identify, track, and store some types of data separately from other types of data.
- Some data exchange participants and data types may require special considerations with regard to uses and disclosures.
- Uses and disclosures that the DxF DSA might limit could include some commercial or private purposes (e.g., marketing).
- Existing data sharing agreements and laws such as the California Consumer Privacy Act (CCPA) may provide a model for how uses and disclosures can be addressed in the DxF DSA.
- It will be important that all participants are held to the same standard of data protections and safeguards to encourage trust among all exchange partners.
- The DxF DSA could require that all participants comply with the Health Insurance Portability and Accountability Act (HIPAA), even if they do not meet the definition of a covered entity or business associate. This would provide a consistent standard for permitted uses across all exchange partners.

- Requiring all DxF DSA participants to comply with HIPAA could be burdensome to organizations that are not considered to be a covered entity or business associate and hamper participation in data exchange.
- The DxF DSA could include provisions that go beyond HIPAA requirements to further protect data and individual privacy.

Specially Protected Information

Schwartz introduced the concept of specially protected information (e.g., data governed by the Lanterman-Petris-Short Act, 42 CFR Part 2) and asked how the DxF DSA should address the issue.

Comments from DSA Subcommittee Members included:

- The DxF DSA could generally require that data obtained under the agreement be used in compliance with applicable law.
- Any provisions pertaining to specially protected information should align with both federal and state law and include a process for ensuring appropriate updates over time, based on changes to law and policy.
- Having knowledge on data provenance would support management of specially protected information, specifically for data that is considered to be ‘protected’ based on its originating source as opposed to the data type.
- Any provisions for specially protected information should be designed so as to avoid causing unintended disparities in access to services (e.g., for those receiving behavioral health services).
- Many existing data sharing agreements do not include a comprehensive list nor discussion of laws that govern specially protected information as applicable laws change over time.
- Stakeholder confusion on the collection, use, and exchange of specially protected information may be alleviated by:
 - Developing a list of all or key relevant laws that is updated on a periodic basis and includes a discussion of considerations to support implementation.
 - Developing and using a ‘universal’ release of authorization form that collects individual-level permissions to release various data among a diverse set of exchange partners.
 - Directing participants to existing informational resources such as the State Health Information Guidance (SHIG).
 - Providing technical assistance to stakeholders.

Minimum Necessary

Schwartz introduced the concept of minimum necessary as described in HIPAA and asked how the DxF DSA should address the topic.

Comments from DSA Subcommittee Members included:

- The DxF DSA should include provisions pertaining to minimum necessary as part of its approach to safeguard individual data and privacy.
- The DxF DSA should require participants to comply with HIPAA, inclusive of the minimum necessary provision.
- Available technology solutions lack the capabilities to share data in a way that is consistent with the intent of HIPAA's minimum necessary provision.
- Social service organizations may not be fully versed in the applicability of minimum necessary regarding the transmission of certain types of data (e.g., case management data).
- The DxF DSA could support an approach that places responsibility for minimum necessary exchange on both the data provider and the data receiver. Such an approach would require organizations to ask for and provide only that data which is needed for a given purpose. The approach may require a process to mediate disagreements between a provider's and receiver's understanding of what is considered to be the minimum necessary in a given situation.

DxF DSA Content: Second Set of Topics

Jennifer Schwartz introduced draft language for the second set of DxF DSA topics which included:

1. Authorizations
2. Special Compliance Provisions and Applicability of HIPAA
3. Cooperation and Non-Discrimination
4. Definitions

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

Authorizations

Schwartz introduced draft language for authorizations.

Comments from DSA Subcommittee Members included:

- The DxF DSA should clarify authorizations based on data transaction methods. The data requestor should hold primary responsibility for obtaining needed authorizations in query-based exchange. The data discloser should hold primary responsibility in a 'push' model of exchange.
- The DxF DSA should include language that unambiguously protects individual privacy, e.g., 'participants shall not disclose data without a legally valid authorization'.
- The authorization approach should include accountability processes in cases when data are inappropriately disclosed.
- The authorization approach should include mediation processes in cases where exchange partners disagree on whether an authorization is valid.

- A universal authorization form would lower the barrier to sharing information as data disclosers would not have to evaluate the validity of varying types or formats of authorizations.
- A consent registry would streamline the approach for collecting and managing authorizations.

Special Compliance Provisions and Applicability of HIPAA

Schwartz introduced draft language for special compliance provisions and applicability of HIPAA.

Comments from DSA Subcommittee Members included:

- The DxF DSA could require that all participants comply with HIPAA, even if they do not meet the definition of a covered entity or business associate.
- State and local governments are each governed by different laws and standards and may require different compliance provisions.

Cooperation and Non-Discrimination

Schwartz introduced draft language for cooperation and non-discrimination.

Comments from DSA Subcommittee Members included:

- Definitions for ‘cooperation’ and ‘non-discrimination’, as well as expectations for participants, should be clear, specific, and unambiguous.
- Provisions pertaining to cooperation and non-discrimination should not place undue burden on participants.
- Because the envisioned participants of the DxF DSA differ from participants of other agreements and networks, care must be taken when borrowing language from existing data sharing agreements.
- The DxF DSA should clarify whether participants are able to delegate responsibility for adhering to cooperation and non-discrimination provisions to intermediary organizations (e.g., health information organizations).
- Provisions for cooperation and non-discrimination should include cybersecurity incidents in the definition of breach and its associated resolution processes.

Definitions

Schwartz introduced draft language for various definitions.

Comments from DSA Subcommittee Members included:

- The DxF DSA should not require participants to adhere to its breach resolution procedures if the data in question are not governed by the DxF DSA.
- The DxF DSA could be made more succinct by referencing legal definitions instead of including full definitions, where appropriate. Doing so would also reduce the frequency of revisions to the DxF DSA.
- There should be a consistent and generally accepted definition for social service organizations. This is particularly important to ensure appropriate privacy and



security provisions if social service organizations will not be asked to comply with HIPAA.

Next Steps and Closing Remarks

Jennifer Schwartz thanked DSA Subcommittee Members and the public for their engagement. Schwartz reviewed project next steps and noted that the next meeting will take place on March 22, 2022.

Appendix 1. Data Exchange Framework Data Sharing Subcommittee Members - Meeting Attendance (February 23, 2022)

Last Name	First Name	Title	Organization	Present
Schwartz	Jennifer	Chief Counsel (Chair)	CalHHS CDII	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
Stewart	Ryan	System VP, Data Interoperability and Compliance	CommonSpirit Health	No

Last Name	First Name	Title	Organization	Present
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