



**California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Data Sharing Agreement Policies & Procedures
Subcommittee
Meeting Summary
Tuesday, October 25, 2022, 10:00 a.m. to 12:30 p.m.**

Attendance

Subcommittee Members in attendance: William Barcellona, Jason Buckner, Louis Cretaro, Matthew Eisenberg, Elaine Ekpo, John Helvey, Sanjay Jain, Diana Kaempfer-Tong, Steven Lane, Lisa Matsubara, Deven McGraw, Jackie Nordhoff, Leo Pak, Mark Savage, Tom Schwaninger, Morgan Staines, Elizabeth Steffen, Lee Tien, Belinda Waltman, Terry Wilcox

Subcommittee Staff and Presenters in attendance: Cindy Bero (Manatt Health Strategies), Rim Cothren (Independent HIE Consultant to CDII), Lamot du Pont (Manatt Health Strategies), Jonah Frohlich (Manatt Health Strategies), Courtney Hansen (CalHHS/CDII), Helen Pfister (Manatt Health Strategies), Elaine Scordakis (CalHHS/CDII), Jocelyn Torrez (CalHHS/CDII)

Public in attendance: approximately 60 public attendees joined this meeting via Zoom video conference or through call-in functionality.

Meeting Notes

Meeting notes elevate points made by presenters, Subcommittee Members, and public commenters during the Data Exchange Framework (DxF) Data Sharing Agreement (DSA) Policies and Procedures (P&Ps) Subcommittee meeting. Notes may be revised to reflect public comment received in advance of the next DSA P&P Subcommittee meeting. Meeting materials, including full video recording, transcription, and public comments may be found on the Center for Data Insights & Innovation (CDII) [Data Exchange Framework website](#).

Welcome and Roll Call

Courtney Hansen, Assistant Chief Counsel, CalHHS Center for Data Insights and Innovation (CDII), welcomed attendees to the second meeting of the DSA P&P Subcommittee. Courtney reviewed the meeting agenda and introduced Subcommittee Members via roll call.

Vision and Meeting Objectives



Courtney Hansen reviewed the vision for data exchange in California as well as the meeting objectives.

Draft Language for First Set of Additional P&Ps in Development

Helen Pfister, Partner, Manatt Health Strategies, provided a high-level overview of the five P&Ps prioritized for near-term development. These P&Ps address the following topics:

- Information Blocking
- Monitoring and Auditing
- Technical Requirements for Exchange
- Real-Time Data Exchange
- QHIO Program

Helen introduced the Information Blocking and Monitoring and Auditing P&Ps as the two P&Ps that would be the focus of the day's discussion. Full texts of these two draft P&Ps are available on the DxF [website](#).

Information Blocking

Helen Pfister introduced the Information Blocking P&P and noted that the draft language largely aligns with federal information blocking rules.

Comments from Subcommittee Members included:

- General
 - Draft language should align with federal information blocking rules and point to federal provisions by reference, instead of incorporating language directly.
 - Applying the federal information blocking rules in their entirety to all participants may impose unnecessary obligations on participants not subject to the federal rules.
 - Instead of focusing on areas of overlap, draft language should focus on ways that Information Blocking requirements under the DxF DSA differs from those under federal rules (e.g., differences in the 'exceptions' to information blocking).
 - The P&P should distinguish between requirements for entities covered by federal information blocking rules from requirements for entities not covered by existing rules.
 - The P&P should be developed keeping in mind the unique considerations for exchanging social services and public health data (e.g., increased risk of individual re-identification), especially as many required signatories are not exchanging such data today.

- The DSA’s approach to addressing information blocking will need to align with its overarching monitoring and enforcement strategy.
- The DSA’s definition of information blocking should not take into account the concept of ‘intent’, which would be challenging to ascertain.
- P&P language should establish clear exceptions to information blocking requirements.
 - There are existing CA state laws that provide additional exceptions to federal information blocking prohibitions (e.g., SB 1419 [linked here](#)).
- Preventing Harm Exception
 - The definition of ‘harm’ in many cases is limited to physical harm which may inappropriately narrow the scope of this exception and exclude harm related to the exchange of mental health or social services data.
 - The P&P may need to identify the entity that will be responsible for determining risk of harm to qualify for this exception.
 - The P&P should address considerations for individuals requesting their information be withheld and implications for data holders.
 - The P&P should clarify “substantial harm.”
 - Many aspects of the federal information blocking regulations, as set forth in paragraph (f), may be unnecessarily complex.
- Privacy Exception
 - Some of the initial content in paragraph (a) may be able to be simplified, potentially pointing to “applicable law” instead of enumerating requirements.
 - State and federal laws on adolescent privacy, mental and behavioral health/substance use disorder care, and reproductive health information remain significant challenges to data exchange.
 - The phrase “case-by-case basis” is not well defined and may not be understood in the same way across contexts (e.g., social services, organizations with multiple sub-programs).

Monitoring and Auditing

Helen Pfister introduced draft language for the Monitoring and Auditing P&P.

Comments from Subcommittee Members included:

- Requests for clarification about the function and obligations of HIOs as it pertains to monitoring and auditing responsibilities.
- This P&P should be developed keeping in mind the enforcement levers that are able to be applied in cases of discovered noncompliance.
- Audits can be invasive and burdensome for organizations, especially if such audits would take place in-person.



- Any sensitive documents sent to the DxF Governance Entity for the purposes of complying with monitoring and auditing requirements should be kept confidential.
- A complaint-focused approach to monitoring would be less resource-intensive than an approach that includes regular, random audits.

Courtney Hansen described the public comment process for P&Ps, noting that the Information Blocking P&P and Monitoring and Auditing P&P would be released for comment later this year. A template for comments will be provided on the [CalHHS DxF website](#).

Content for Second Set of Additional P&Ps in Development

Rim Cothren, Independent HIE Consultant to CDII, introduced content for two additional P&Ps in development:

- Technical Requirements for Exchange; and
- Real-Time Data Exchange

Technical Requirements for Exchange

Rim introduced draft concepts for the Technical Requirements for Exchange P&P.

Comments from Subcommittee Members included:

- There are a number of methods for exchanging event notifications other than HL7 v2.
- General agreement on allowing for FHIR-based exchange to align with industry trends.
 - The Gravity Project published an Implementation Guide to support FHIR-based exchange, [linked here](#).
- It would be helpful to clarify how social services organizations will be expected to participate in exchange (e.g., via a QHIO or a community information exchange).
- It may be helpful to allow recipients and subscribers of event notifications to specify how they would like to receive notifications (e.g., via Direct, FHIR push, etc.).
- Broadcast requests should be limited to avoid overwhelming organizations with a large volume of requests, and when necessary, be appropriately tailored to avoid exchange of data beyond the minimum necessary.

Update to DSA Language

Courtney Hansen noted that a revision was being made to the DSA to remove CalHHS as a signatory. Courtney clarified that this revision does not change or diminish CalHHS's role and responsibility to oversee the DxF.

Signing the DSA



Rim Cothren noted that CalHHS is developing a solution that would allow entities to sign the DSA electronically through a web-based self-service application. More information is forthcoming in November. Rim noted that mandatory DSA signatories should be reviewing the DSA now to plan for execution by January 31, 2023.

Public Comment

Courtney Hansen opened the meeting to public comment, which included¹:

- Lucy Johns expressed concern about the requirement to use the IHE XDR standard, noting that other networks such as Direct do not use this standard. Lucy also emphasized the importance of including the consumer perspective in DSA P&P Subcommittee discussions.

Next Steps and Closing Remarks

Courtney Hansen reviewed next steps and thanked Members for their engagement. She noted the following upcoming meetings:

- DSA P&P SC Meeting #3 December 15, 2022, 9:00 AM to 11:30 AM
- DSA P&P SC Meeting #4 January 26, 2023, 9:00 AM to 11:30 AM
- DSA P&P SC Meeting #5 March 9, 2023, 9:00 AM to 11:30 AM

¹ Name spelling approximated based on verbal statements.



Appendix 1. Data Exchange Framework Data Sharing Agreement and Policies & Procedures Subcommittee - Meeting Attendance (Oct 25, 2022)

Last Name	First Name	Title	Organization	Present
Barcellona	William	Executive Vice President for Government Affairs	America's Physician Groups	Yes
Buckner	Jason	Chief Information Officer & Chief Technology Officer	Manifest Medex	Yes
Cretaro	Louis	Leady County Consultant	County Welfare Directors Association of California	Yes
Eisenberg	Matthew	Medical Informatics Director for Analytics and Innovation	Stanford Health	Yes
Ekpo	Elaine	Attorney	California Department of State Hospitals	Yes
Helvey	John	Executive Director	SacValley MedShare	Yes
Jain	Sanjay	Manager, Data Analytics	Health Net	Yes
Kaempfer-Tong	Diana	Attorney	California Department of Public Health	Yes
Kim	Helen	Senior Counsel	Kaiser Permanente	No
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
Nordhoff	Jackie	Director of Regulatory Affairs	PointClickCare	Yes
Pak	Leo	Chief Technology Officer	Los Angeles Network for Enhanced Services	Yes
Savage	Mark	Managing Director, Digital Health Strategy and Policy	Savage & Savage LLC	Yes
Schwaninger	Tom	Senior Executive Advisor, Digital Ecosystem Interoperability	Los Angeles Care	Yes
Staines	Morgan	Privacy Officer & Asst. Chief Counsel	California Department of Health Care Services	Yes
Steffen	Elizabeth	Chief Information Officer	Plumas District Hospital	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