



California Health & Human Services Agency Center for Data Insights and Innovation

Data Exchange Framework Implementation Advisory Committee and Data Sharing Agreement (DSA) Policies and Procedures (P&P) Subcommittee Meeting Chat Log (9:00 AM – 11:30 AM PT, May 15, 2025)

The following comments were made in the Zoom chat log by Members of the IAC, DSA P&P Subcommittee, and staff during the May 15, 2025, meeting:

From Steven Lane to all panelists 09:07 AM Data needs start at conception, not birth.

From Jackie Nordhoff to all panelists 09:08 AM Jackie Nordhoff, Had to step away during attendance but here now-Thank you

From Matthew Eisenberg to all panelists 09:16 AM https://www.healthit.gov/isp/standards-version-advancement-process

From Matthew Eisenberg to all panelists 09:18 AM California SHOULD NOT get ahead of federally required USCDI version advancement. That will not work with our vendors or our organizations! I keep reminding folks of this point. (And I can't post to everyone).

From Dan Chavez to all panelists 09:19 AM Please share the POLST award reference

From Steven Lane to all panelists 09:19 AM Agree with Matt E. Focus on USCDI V3 for next year.

From Belinda Luu to all panelists 09:20 AM I agree with Matt.

From Courtney Hansen to all panelists 09:20 AM Thanks, Matt. We are working to address this now.

From Matthew Eisenberg to everyone 09:21 AM

https://www.cms.gov/newsroom/press-releases/cms-seeks-public-input-improving-technology-empower-medicare-beneficiaries

From Aaron Goodale to everyone 09:29 AM Would you please share the link to the public directory listing?

From Rim Cothren, CalHHS CDII to everyone 09:29 AM @Dan, you can learn more about EMSA's advancement of an electronic POLST registry at https://emsa.ca.gov/polst/.





From Matthew Eisenberg to everyone 09:30 AM

At Stanford Health Care, we do not use the directory since we typically use this sort of directory for the management of exchange endpoints for TECHNICAL data exchange on a network. Since we have not actual network, we don't use this directory.

From Rim Cothren, CalHHS CDII to everyone 09:31 AM @Aaron: You can find the public listing on the DxF webpage at https://www.cdii.ca.gov/committees-and-advisory-groups/data-exchange-framework/. Look under the first panel "DSA Signatory Portal and Participant Directory".

From Tom Schwaninger, L.A. Care Health Plan to all panelists 09:31 AM Good point, John!

From Cameron Kaiser to all panelists 09:32 AM Is it intended to be able to access the .csv without logging in?

From Jason Buckner to everyone 09:32 AM

Another suggestion: if the org selects a national network, it would be helpful to have a field to link them to their entry in the eHX/CQ directory such as a HCID/OID

From Rim Cothren, CalHHS CDII to everyone 09:33 AM Yes, the CSV file is accessible on the DxF webpage without logging into the portal.

From John Helvey to everyone 09:33 AM Agree with Jason on identifying national network chosen

From Steven Lane to everyone 09:36 AM Identify national networkS and frameworks utilized, perhaps with links to the participant's directory entry in those other networks.

From Matthew Eisenberg to everyone 09:36 AM Publicly available data on eHealth Exchange Participants can be found here: https://ehealthexchange.org/participants/

From Steven Lane to everyone 09:38 AM

To Felix's point regarding validating directory entries, the TEFCA framework is developing a vetting process for each exchange purpose, to assure that directory entrants are appropriate to utilize the purposes for which they intend to exchange. This is very specifically meant to build and maintain trust in the framework.

From Matthew Eisenberg to everyone 09:41 AM





The Sequoia Project has a working group focused on Privacy and Consent. We should learn from this group: https://sequoiaproject.org/interoperability-matters/privacy-and-consent-workgroup/#download-whitepaper

From Rim Cothren, CalHHS CDII to everyone 09:41 AM Thanks, Matt.

From Jackie Nordhoff to everyone 09:51 AM Does Care partner= all providers?

From Sanjay Jain to everyone 09:52 AM

In Pathway #2 and #3 (without Intermediary) how would Care partner or Individual be able to send consent info to CMP?

slide#26 has one way data flow from CMP to Care Partner / individual

From Matthew Eisenberg to everyone 09:54 AM

In my recollection, we've tried something similar at a state level in our CA State Advanced Health Care Directive Registry. This is generally manual, voluntary and not integrated into technical workflows and has not proven to be scalable or useful? How will this be different?

From Sanjay Jain to everyone 09:54 AM never mind, I see 2 way. I believe it would be through API

From Jonah Frohlich (he/him) | Manatt to everyone 09:58 AM

@Matthew Eisenberg: We are incorporating lessons learned from the California ePOLST pilot, have had conversations with Oregon's own ePOLST program, and are considering recommendations from Sequoia (the paper you referenced) and others to help inform this program. The manual aspect you mentioned has to be overcome with as much automation (digitization and structured data) of forms and a standardization of the form itself. And to your point, making this voluntary for all will likely limit its deployment; making it compulsory in certain contexts is being considered.

good point Amie, well taken thank you

This is the effort Steven mentioned in WA: https://www.hca.wa.gov/about-hca/programs-and-initiatives/electronic-consent-management

DHCS and WA HCA presented at an MESC panel last year on consent management. WA is continuing to iterate as they try to deal with interoperability and workflow challenges

From Deven McGraw to all panelists 10:04 AM

This is great - I'm less confident that there will ever be a national consent registry, and it's important to get an effort started in CA that meets our needs and is consistent with legal requirements (i.e., obtaining consent when its legally required and not over-rotating to a "consent for all" regime).





From Deven McGraw to everyone 10:07 AM

Reposting to Everyone: This is great - I'm less confident that there will ever be a national consent registry, and t's important to get an effort started in CA that meets our needs and is consistent with legal requirements (i.e., obtaining consent when it's legally required and not over-rotating to a "consent for all" regime).

From Jonah Frohlich (he/him) | Manatt to everyone 10:07 AM

Agree Deven - the Sequoia report (I think Steven was a co-chair of the workgroup) described a state example and evoked California and specific state laws (CMIA) that would be implicated. Some states like CA have privacy rules and a federal solution would need to accommodate all of them. And there's no federal initiative to establish such a registry. But we do need to look at and consider adopting federal standards so that anything CA does is aligned.

From Deven McGraw to everyone 10:09 AM

This approach also has the advantage of allowing for data exchange in many/most cases even if the individual hasn't executed the form (i.e., they don't have data/needs where consent is legally required).

From Steven Lane to everyone 10:15 AM

Note that Deven was also a co-chair of the Sequoia Privacy & Consent Workgroup that published the white paper linked above by Matt.

* by Jonah.

From Louis Cretaro to everyone 10:16 AM

This will be my last meeting; I am retiring in June. It's been a privilege to be a member of the DSA Policy and Procedures Subcommittee these past years.

Best wishes

From Jonah Frohlich (he/him) | Manatt to everyone 10:17 AM Congratulations Louis! Thank you for your service to the DxF! From Steven Lane to everyone 10:17 AM

Congratulations, Louis. Your input here has been consistently well informed and insightful.

From Steven Lane to everyone 10:27 AM

The fact that the RFI is coming from ASTP/ONC suggests that that office has survived the cuts and will participate in ongoing federal advancements.