



## California Health & Human Services Agency Center for Data Insights and Innovation Data Exchange Framework Technical Advisory Committee (TAC) Meeting Chat Log (12:00 PM – 1:00 PM PT, June 12, 2025)

# The following comments were made in the Zoom chat log by Members of the TAC and staff during the June 12, 2025, meeting:

4:54:39 From David McCann to Hosts and panelists: Good morning all

15:15:37 From Ambrish Sharma to Everyone: Should the changing immigration legal landscape be included in our conversation about consent management?

15:15:46 From David McCann to Hosts and panelists: If it will exist, let's have a timeline of " by when".. What year is the envisioned " will" ?

15:16:01 From Catalina Cole | Manatt Health to Everyone: For Discussion : Should DxF converge on a shared model for consent management?

15:16:09 From Rita Torkzadeh to Hosts and panelists: By "Shared" does that mean centralized?

15:17:06 From Sara Rogers to Hosts and panelists: My memory from last meeting is also that our department representative emphasized the importance of data providence being reflected/designed in the consent management processes -- is that assumed to be inclusive in the statement?

15:17:17 From David McCann to Hosts and panelists: I don't think ' WILL " and " Status quo" are the only BINARY scenarios, Rim

15:17:56 From Catalina Cole | Manatt Health to Everyone: Please direct your chats to 'everyone' so they are visible to members of the public.Thank you.

15:18:01 From Rita Torkzadeh to Hosts and panelists: There are risks to centralization

15:18:53 From Jonah Frohlich (he/him) | Manatt to Everyone: @Sara: I would suggest that data provenance does need to be reflected in the design. There needs to be awareness of the origin of the consent (and other aspects) that help everyone understand provenance

15:18:53 From David McCann to Hosts and panelists: Centralization is the antithesis of the principles of the DXF published roadmap, I believe, where it calls out ' innovate locally: "

15:19:38 From Sara Rogers to Everyone:





My memory from last meeting is also that our department representative emphasized the importance of data providence being reflected/designed in the consent management processes -- each source of data has unique requirements/protections governing consent and sharing. Is this assumed to be inclusive in the statement?

15:20:10 From Rita Torkzadeh to Everyone: Need to weigh risks/benefits of centralization vs. federated model

15:20:33 From Adam Davis to Hosts and panelists:

I agree with Julie's comments that there may not be enough resources for DxF to take on this important work. The status quo is far less than ideal, but this is an enormous project that would need significant financial support to realize.

15:22:31 From Julie Silas to Everyone:

Also - many small organizations who may have 1-2 staff at most, are collecting the releases of information (in CoCs, they call them ROIs, which is super confusing when you are talking with a health population) - they would not likely be participants in DxF - or any required system that has to be paid for or requires administration and administrative costs. There is so much to learn about the practical reality of how the experience of consent is implemented in so many different scenarios. What is the journey map for all different types of people on the ground, etc.

15:22:34 From Rita Torkzadeh to Hosts and panelists:

FYI- Don't have a hand raising capability for some reason so apologies if I chime in without a hand

15:23:34 From Ken Riomales to Everyone:

I don't necessarily view a common data model and a state run centralized platform as mutually exclusive. We can have both.

15:23:59 From Julie Silas to Everyone: Offer guidelines and boundaries or best practices that are patient/client-centered and are feasible for the providers who work with them

15:24:10 From Rita Torkzadeh to Everyone: Identity is a key component

15:24:49 From Robby Franceschini, Blue Shield of CA to Everyone: +1, Rita

15:24:51 From Ambrish Sharma to Everyone: Agree with @Ken

15:25:00 From David McCann to Hosts and panelists:

DXF creates a forum and mechanism... and has 4000 signatories and 740 grantees. I believe this dialog IS the mechanism. And the output COULD be a Set of initial Data models.. (currently 5 being notionally obvious ". Let innovation occur by entities (Grantees) and the innovation.. that is already occurring. A distributed / federated data model is what I advocate for.. API's can accommodate that over time.

15:26:33 From David McCann to Hosts and panelists:





Re Ken's comment, I believe Ken the data model comes first, and any centralized repository is a later / secondary.. choice the state is free to do.. but I believe United Way 211's will have to innovate and already have on Consent, and then can " evolve" to perhaps a richer model that the State / DXF dialog cals out.

15:27:04 From Alice K - Events to Rita Torkzadeh(direct message): Thanks, Rita. I changed a setting so you should now see Raise Hand more easily at the bottom of your Zoom screen. Please let me know if you have any further issues!

15:27:36 From Rita Torkzadeh to Alice K - Events(direct message): thanks I see that!

15:28:51 From Jeff Jarrett to Hosts and panelists:

I agree with Han's point to ensure we look to other states to see what models and systems exist to help ensure efficient use across states. While DxF may not need to "own" the central data store, it seems we need a central repository to ensure that each service provider, and system only need to make a call to one place to pull current consent information and push updates to.

15:28:53 From Catalina Cole | Manatt Health to Everyone: What are the components for a logical model for consent for exchange of different types of information?

For example, where it was collected, when it was collected, what types of data it governs, who it was collected from (individual or legal guardian), etc.

How do you reconcile consent collected in different places and for different purposes?

Can reconciliation be automated and operationalized?

How do you establish trust so that a Participant will act on consent obtained by another Participant?

15:30:05 From Sara Rogers to Everyone: Curious if there are examples for the "catalog" deliverables that Eric Jahn just mentioned.

15:33:14 From David McCann to Hosts and panelists: Innovation can occur, and coherence is where the innovation adopts a "proposed standard" data model with semantic terms

15:34:41 From Robby Franceschini, Blue Shield of CA to Everyone: For Q1, in addition to Eric's comment on revocation, whether a consent is new or an existing one is being amended/updated

15:35:05 From Derek Plansky to Everyone: the fundamental terms need to be defined in advance so that they are understood universally

15:35:54 From Jeff Jarrett to Hosts and panelists:

Has there been any time and effort put into reviewing and assessing best practices for consent mgmt within the US or abroad? If so, what are some of the findings? If not, I think time and effort should be put into this.





15:35:58 From Rita Torkzadeh to Everyone: Who reconciles consent? the requesting or receiving org?

### 15:38:08 From Ambrish Sharma to Everyone:

For the question about logical model, timeline of the consent would be important, with periodic reconciliation if the consent is still valid or not. Change in an individual's mental status from the time consent was given should also be considered in alignment with the medical/legal framework.

## 15:38:55 From Eric Jahn to Everyone:

Good question @Sara Rogers. I think there are examples in the general web technology sector for any industry of a registry of web endpoints, with jurisdication/domain/date updated/etc. metadata for each cataloged web endpoint. These directories/catalogs of endpoints were part of the SOCI Consent Workgroup in 2024 that took place. https://stewardsofchange.org/wp-content/uploads/sites/2/2022/01/Button-1-19-22-SOCI-Consent-Scan-Report-Final-11-22-21.pdf

15:40:42 From Derek Plansky to Everyone:

how many people are in multiple programs? and does program become too granular a concept to reasonably manage if there are thousands of different programs?

15:41:42 From Eric Jahn to Everyone:

@Robert Franceshini - Yes, I agree, that would be very useful for avoiding confusion as to what is the intent of the message being published.

15:42:12 From Ambrish Sharma to Everyone: Situations like victims of domestic violence or human trafficking should have special

consideration when developing a logical consent model.

15:42:20 From Rita Torkzadeh to Everyone:

Does how people get into programs, such as a clinical referral, affect this idea of program-based logic (rather than patient of person-centric)?

15:42:49 From David McCann to Hosts and panelists:

I advocate for an Amazonian style of innovation which is "invent and simplfy". I believe we work back from the. "Client", and Consent is "what is needed to solve for the needs of this person, for that persons needs, and the consent needed". It could be as simple as 13 Data Elements ... which are captures, relative to a "Client record".. United Way 211' is now studying this based on this working group. We have a "V1 Consent for certain programs. I see us " evolving a consent. Type". Depending on the program and entity.

15:43:14 From Eric Jahn to Everyone:

We need a record locator/url, to retrieve an existing/stored consent.

15:44:25 From Sara Rogers to Everyone:

in our world it's not ever SUD yes/no --> its yes in this context and it could be no in another 15:46:20 From David McCann to Hosts and panelists:

I believe that at a county level, , Eric, innovation on. Consent Capture will happen PROGRAM by PROGRAM. We will evolve.. and for Ken Rioomales, I would argue we build out the "what is needed', by doing so on a set of larger programs that may be common. Orange County has





2500 Gov/ Social Impact care programs.. the Program is critical. United Way OC 211 is operating ~ 150 programs.. with 180 CBO's. Program innovation HAS to move at the timeline of the funded Program. We can't wait for centralization. We can align to a standard model.

15:47:30 From David McCann to Hosts and panelists: Would a guidance be, Linette, that all DXF participants are encouraged to adopt the ASCMI data fields.. and is that the V1 data model.

15:48:15 From David McCann to Hosts and panelists:

The provenance discussion is a GOOD one. Which entity captured the Consent, and HOW. For which programs. ?

15:51:47 From David McCann to Hosts and panelists:

Rita, I believe the person will give consent in multiple forums.. a Hospital, or a 211 Call Center, or a Food Bank, or a Mental Health clinic. So the ENTITY who captures it.. and for WHAT purpose, is important. And WHEN. We are really in these sessions doing - is it fleshing out the parameters we need to design for. The person/ client is in multiple systems. Today, we start with thousands of entities and no central repository. Intermediaries play a role here. 211 as an intermediary, has to solve for this.

15:53:51 From David McCann to Hosts and panelists:

Hans, can we simplify down to perhaps 5 Consent Types.. this group is already teasing out " different populations of focus". (Eg Youth/Adolescent, Person experiencing SUD, or a person with Food Insecurity needs or experiencing Homelessness.)

15:55:03 From Sara Rogers to Everyone:

Given the clarification that this functionality is intended to be limited to the broad applications of consent I believe we would especially benefit from a catalog of terms, fields, entities so that those service systems that need a more nuanced level of consent decision making can use the tools being discussed and correctly understand what further steps they may need to take.

15:56:10 From Julie Silas to Everyone:

Just thinking about federal comments. For example, the practice in homeless systems of care is to either list the entities where the client is agreeing to have their data shared OR list out the members of the homeless system on their website and reference the website in the consent document, to provide updated lists, etc. If similar requirements of consent docs exist in other programs, this is going to be hard to implement. For example, many clients in the homeless system would not consent to have law enforcement have access to their data

15:56:25 From Julie Silas to Everyone: \*federal requirements

15:56:40 From Hans Buitendijk to Everyone:

David: I would agree that certain populations may have like data they wish to apply consents to, or are being asked for consents to share before it can be used. I would suspect though there will be more population types than 5 (but one has to start somewhere) and more uses cases that are prevalent to enable computable consent rules as a starter set.

15:58:06 From Robby Franceschini, Blue Shield of CA to Everyone:





Another consideration about thoughtfully translating data domains and types include in standards into plain language for use in authorization/consent forms. Health care organizations describe PHI types of data in many ways today.

#### 15:59:43 From Eric Jahn to Everyone:

I just had the thought that possibly a person could store/retrieve a copy of any/all of their consents in a personal data locker, hosted by a business or a service provider, or even self-hosted. This would empower consumers and help the to also revoke any/al outstanding consents.

15:59:51 From David McCann to Hosts and panelists: Rajib,, I might interpret "sector' in DXF terms as " populations of focus and Programs in a county"

16:00:39 From Diane Dooley to Hosts and panelists: Can you repost the website?