

California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Implementation Advisory Committee
Data Sharing Agreement Policies and Procedures Subcommittee
Meeting 14 Public Comment Log (1:30PM – 3:30PM PT, April 10, 2024)

The table below shows public comments that were made verbally during the April 10 virtual meeting. Additional comments can be found in the meeting’s “Q&A Log” posted on the CalHHS Data Exchange Framework [website](#).

Count	Name	Comment
1	Kayte Fisher, CDI	Per some of the comments that have been raised with regard to consent and opting out of consent, the Department of Insurance is primarily a consumer protection agency and so from our perspective, consent is worthless and meaningless if it cannot be revoked. It’s not real consent if a patient fees a) forced into it or b) can’t make a decision and then decide that they want to change their mind. That’s a hallmark of true informed and free consent. And I can just tell you from my own personal experience in the last week, I have regular health insurance just like all state employees, and I called Shield and I asked if I could, please, revoke my consent for Shield to share my information via the Data Exchange Framework. Unsurprisingly, the person who answered the phone had no idea what a Data Exchange Framework is and had, even after talking with two layers of management, had no idea how to accommodate my request. So, I felt like that was a pretty fair entry point and then just yesterday, I get my own healthcare at UC Davis Health System, a very large health system, and I requested both at the front desk of the radiology department and then also later via the Patient Relations Office, which they’re sort of a higher-level customer service department, if I could revoke my consent for any of my data being shared via the Data Exchange Framework. Again, absolute blank stares. No one had any idea how to even remotely go about that. So, I am obviously better informed than most people and I feel like I have better abilities to make these requests, and if I can’t get any knowledgeable response

Count	Name	Comment
		<p>at all, then I'm pretty sure that no other California consumer is also getting any response. So, I think a technical ability on paper to revoke consent is one thing, but a practical, real-life ability is a very different thing. And the other thing that I've raised before is that the department is very strongly interested in seeing the new policies and procedures developed specifically around sensitive services and the maintenance of privacy and security around that data. And those two things, both consent and specifically around sensitive services, those things dovetail almost completely.</p>
2	Lucy Johns	<p>I really appreciate all this conversation about opt out. And I would say that we have the DxF because there was pressure in the legislature to require exchange. I'm hoping that the DxF can address the issue of opt out so that we don't need to be going to the legislature to protect ourselves. Thank you.</p>

Total Count of public comments: 2