



California Health & Human Services Agency
Center for Data Insights and Innovation
Data Exchange Framework Stakeholder Advisory Group
Data Sharing Agreement Subcommittee
Meeting 5 (March 22, 2022, 12:00PM – 2:30PM PT)
Public Comment Log

The table below shows public comments that were made verbally during the March 22nd virtual meeting. Additional public comments can be found in the meeting’s “Q&A Log” posted on the CalHHS Data Exchange Framework [website](#).

Count	Name	Comment
1	Jonathon Feit	<p>Hi thanks very much. Can you hear me? Hey Rim good to see you again. So real briefly and since it was touched on earlier about the fact that our State has a wonderful habit of creating sort of multiple parallel systems that then need to be reconciled back to each other, I wonder if we can have some specific discussion around the unknown patient. And this is not theoretical at all. I’m here on behalf of the California Fire Chiefs Association, the California Fire Chiefs, EMS Agencies etcetera, folks who are going to be engaging with patients out in the field where they are possibly unable to speak for themselves. They may be of an altered mental status that may be due to substances of one kind or another, dementia, injury, a variety of different use cases - certainly it brings in social equity issues.</p> <p>But also we are talking pretty aggressively - I know Rim and I, of course, have had this conversation many times around POLST, end of life orders. So to the degree that you do not want to get the end of life order wrong because you looked up Rim Cothren instead of Robert Cothren. So to the degree that we are talking about parallel tracks, again, different registries that will have different thresholds for identifying and then you’ve got this massive population of people who are affected where they can’t say here’s my actual name, you may have a friend nearby who says this person is Rim I don’t know you any other way, for example. So can we talk a little bit about an unknown patient, because the identity issues in a high triage environment can be everything. And you really don’t have any room for error in those types of use cases, where you might in a more controlled setting of care. Thanks very much.</p>

Count	Name	Comment
2	Jerry Hall	<p>Okay, thank you. Hi everyone. My name is Jerry Hall, I'm from San Diego and I'm an advocate in a number of areas around open government and the data exchange between the criminal, legal, and behavioral health systems. My comments here I'll also email because they're much longer. But my underlying concern and the comments that I'm sending you focus on the potential misuse of one's health data, especially by those in government and the private sector. And by those who traditionally seek to continue to target our marginalized communities. Additional concerns include highly probable data use by corporate entities that may simultaneously operate in the healthcare marketplace, yet also have business concerns that benefit from that same data for other purposes, like targeted marketing which I believe would be much more difficult to track. So if they're using it for healthcare and then come in, under a different umbrella using the same data for their marketing. I believe that we all know that data can be a double edged sword, it can both build and remove barriers. We should never forget that, as a society and in both private and government sectors we have traditionally and will likely continue to seek opportunities that reinforce, grow and sustain our biased and racist practices. So ultimately, what I'm after is championing line level control of our data. So if I decide that either categorically or you know by practitioner if I want to eliminate the ability for someone to use my data I should have that control, no matter what the technological difficulties are today. If we present the ideas and framework, I think that that technology will be able to catch up pretty quickly. So not only have line level access but also I wanted to know what entities are using my data. So if Google has a partnership agreement with a data exchange entity, I should be able to see that Google has access to my data and this isn't about, you know, eliminating control, it's about making sure that consumers have the ability to know and understand who's accessing their data, so they can advocate for themselves. Thank you.</p>

Total Count of public comments: 2