

Hi John and Jonah,

Nice to see you both yesterday. Here is some quick feedback on the topics discussed. I also want to flag in advance that I cannot attend the last/June meeting. I'm not sure if you plan to do any final "decision making" at that meeting, but I am happy to provide my input ahead of the meeting if there is an opportunity. Thanks so much for all of your work and collaboration.

Kiran

Governance: We support the proposed governance model and would want to ensure strong conflict of interest policy such that each member of the governing board is focused on the interests of Californians/consumers. We would also like to see more attention to building in mechanisms to gather input from consumers so that the governing board has data available to them to make policy decisions.

Consent: While we understand the desire to streamline consent processes, we think the biggest issue is ensuring that consumers are able to make informed, supported decisions. Any streamlining should be accompanied by strong protections for consumers including culturally and linguistically relevant education and the support of patient advocates/navigators. In addition, if a universal consent form is considered, consumers should have support to revisit their decision as their health information changes, particularly as it relates to sensitive information. As the data exchange framework is implemented and more information flows between more entities, consumers will have more and more complex decisions to make and investments should be made in appropriate consumer support.

Digital Identity: We support the digital identity attributes outlined on slide #46. In particular, we agree that race, ethnicity, language, gender identity, social security number, and DMV/DL number should NOT be a part of the digital identity.



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