



John Ohanian
Chief Data Officer
California Health & Human Services Agency
1205 O St.
Sacramento, CA 95814

May 19, 2022

Dear Mr. Ohanian:

The Electronic Frontier Foundation appreciates the opportunity to provide feedback on the models and strategies presented at the various data exchange meetings pursuant to A.B. 133. Data sharing in general has become controversial in today's world. Privacy concerns have only grown as the pandemic exposes many weaknesses in our health care system, including public health.

It is difficult to provide advice on a governance model when the function and scope of a future oversight or policy body is unclear. There should be no question, however, that governance around health data information technology must place great value on data privacy, security, and integrity, and prioritize the interests of diverse patients and consumers, including ensuring that they are represented within the structure.

We are concerned that the discussions that we have attended seem to prioritize data sharing among HIE participant entities with relatively little attention to patient preferences, awareness, or expectations. While we appreciate the potential benefits of data sharing, we are concerned that the draft agreement is insufficiently attuned to concerns about data "leakage" beyond patient awareness or expectations.

As others have noted, this is a very different model than one that relies on established care relationships and patient preference to trigger the exchange of protected health information via query and/or push methodologies. The very technologies that permit greater authorized data sharing can also permit greater unauthorized data sharing.

Of particular importance in the current environment is the sensitivity of certain types of health information, such as data related to seeking or providing abortion services. Will the data sharing agreement and policies/procedures allow out-of-state actors who do not respect reproductive rights, including out-of-state law enforcement, to obtain data about persons seeking or providing abortions in California? Will patients be able to prevent the sharing of information that they consider confidential? Other vulnerable populations should also be concerned, given the inclusion of social determinants of health (SDOH) data: domestic violence and human trafficking survivors can be at risk from provider disclosures; some out-of-state public officials even regard gender-affirming care for transgender children to be child abuse.

Finally, we hope that funding can be provided for modernizing technology in the public health sector. Much of the current public health data infrastructure is outdated in terms

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of capacity for modern health information exchange. Many programs still fax charts to help with clinical co-management, case management, quality improvement/registry management, and even outbreak management. Without such modernization, public health could be a truly weak link in the chain of health privacy and security.

Sincerely,

A handwritten signature in black ink, appearing to read 'Lee Tien', with a stylized flourish at the end.

Lee Tien
Legislative Director and Adams Chair for Internet Rights
Electronic Frontier Foundation