

April 7, 2022

TO: Data Exchange Framework Stakeholder Advisory Group
Emailed to: CDII@CHHS.CA.gov

FR: Jerry Hall

RE: Public Comment, Meeting #7

Thank you all for the work you are doing to develop recommendations to optimize the benefits and value our health data could prove to us individually and collectively.

To that end I believe there are some important considerations as you continue your work including

1. Identifying the personal, corporate, and societal social value of data.

- a. **Personal Value of Health Data**

I can attest to being an active participant in my healthcare, especially over the last several years because I diligently documented every entity, appointment, documents, and results – from blood labs to x-rays on my phone. Having that at my fingertips helped multiple times as data wasn't shared as effectively and my doctor today was basing their course of action on all the available information they had at that moment.

- b. **Corporate and Government Value of Health Data**

On the corporate side there are many actors, for instance Quest Diagnostics, parent of ExamOne, and a product called ScriptCheck. This data includes 24+ billion pharmaceutical prescriptions along with our personal identity information, and a report and score generated by the company to predict and score our various ailments

Another example is Google Health, who has apparently backed an effort through various other companies they have rebranded or partnered with themselves, and who operate a substance abuse disorder treatment center called OneFifteen in Dayton Ohio since 2019. This is an example of a corporation ultimately having a relatively obstruction-free pathway to our health data.

Corporations have trillions of reasons to access and use our data. Political entities have even more incentive. We saw for instance how Cambridge Analytica apparently built profiles for hundreds of millions of Americans including up to 500 data points on each of us. They then used that data, including our financial and social networking data to micro-target individuals with up to tens of thousands of variations of political advertisements. One can

argue this was a significant contributor to the level of fragmentation and division our county is experiencing today.

Corporations and government themselves have interests in reducing health care costs, and other burdens on society those who are not well may 'impose' on society at large. Such motivation might lead these stakeholders to pursue eugenic-focused policies and practices 'for the good of society' that ultimately enable them to steer populations through medical, legal, and social controls that help reduce the population levels that 'cost' society disproportionately.

c. **Societal Social Value of Health Data**

The third is the social value of data. To this end I believe there is a higher purpose for the use of deidentified data. One caveat is the ability for corporate marketers to reconnect such data using myriad other data points so that is a challenge we must consider. That said, even though I may not agree to share my data with or for corporate uses, there is a higher purpose that transcends my personal fears. That is, how can that data be used to benefit society as a whole while simultaneously not be used to strengthen biased care, or otherwise target or exclude populations based on racial, cultural, or other personal factors.

Although unsaid here, I assume most all agree on the absolute overarching

2. **Health Data and the Intersections of our Criminal-Legal and Health Systems**

- a. There are many ongoing efforts nationwide to standardize and exchange criminal-legal, crisis care, public health, and behavioral health data systems. Speaking from a moderate to high level of lived experience within each of these systems at the consumer, community leader, and advisory board level, I believe there are many opportunities to dramatically improve how we address populations caught up in the criminal legal systems.

We have a unique opportunity to affect those locked up inside, those on their way out and returning to society, stemming the flow of those entering the system from the juvenile legal and education systems, and the half of our previously incarcerated that will likely recidivise.

As you are aware there are many system-specific laws that overlap and duplicate intended protections of consumer data. You might consider recommending such laws are reviewed on a statewide and national level and modified to include new possibilities for government to achieve significant financial benefit, and by extension for society to achieve a much different and higher quality-level of education, legal, and health outcomes.

We cannot watch our well-intentioned legal protections overrun our potential of developing a truly transformative society.

3. **Consumer-Level Education, Access, and Control**

In considering recommendations and the early design and development of consumer-level education, access, and control over their health data, we must

include such elements at the earliest possible opportunity. Delaying these capabilities because of the challenges in creating sufficient policies, practices, and technological tools early on excludes leadership-stakeholders such as this body, and the authorities you establish to carry this work forward, from meaningfully including the high value contributions from consumers and stakeholders advocating for them.

Further, as you decide recommendations prioritizing or delaying the education and abilities of consumers to access and maintain macro-level control over their health data at the earliest opportunity, we should consider that overcoming anticipated difficulties are mere challenges that, given the chance, innovators will absolutely overcome. If this is truly a consumer-centered initiative let's not marginalize or deprioritize their meaningful and informed participation.

Conclusion

In conclusion, I believe these are the top priorities that we must put front and center. That includes, 1) the personal, corporate, and government access and level of use of data from multiple systems, 2) protections of individual rights and privacy by ensuring extreme control by external facing or potentially conflicted internal profit-first entities, 3) how our data can be utilized to improve and dramatically reduce impacts on our legal and health systems through more effective sharing policies, and last but not least, 4) high levels of consumer education, access, and control over one's data.

Ideally, we are all focused not only on financial and institutional benefits of developing these systems, policies and practices but, more importantly, how we can ensure the work we are doing attacks and decimates systems, policies, and practices that have often intentionally and by design, systematically harmed racial, cultural, gendered, financial-status, and geographic-oriented populations.

To this end, there appears to be a missed opportunity to include privacy-related advocacy organizations (ACLU and EFF come to mind) as well as peers and individuals with lived experience who could serve on this and related advisory boards and committees. There is the potential of an echo-chamber effect if only government and healthcare system-actors are at the table. Advocates and peers are prone to ask tough questions and to that end I encourage you to include more of these roles within these bodies.

That all said, it seems that also including corporate entities that will likely seek to gain immediate access to as much data as possible (Google and Facebook come to mind) would be beneficial provided they were willing to include their business-oriented goals in a spirit of developing optimal policy.

Thank you very much.