

March 14, 2022

TO: John O'hanian

FR: Jerry Hall

RE: Data Exchange Framework - Guiding Principles Feedback

I read with great interest the piece you wrote about the work of the Stakeholder Advisory Group with the California Health and Human Services Agency (CalHHS) as they develop our future CalHHS Data Exchange Framework (DxF).

I understand the primary draft is named 'California Health & Human Services Agency Center for Data Insights and Innovation Data Exchange Framework Guiding Principles'.

I had some thoughts and would appreciate your guidance as to how I could best query this Advisory Board as they finalize these principles. I also tried to identify the apparent corresponding principle heading from the draft. Primary concerns include:

1. **Advisory Board Composition** | There is an apparent lack of California healthcare consumer-stakeholders as primarily consumers or caregiver representatives with lived experience serving on the current Advisory Board. Although some board members likely have such lived experience, it is not evident that both consumers of our private and our Medi-Cal funded care delivery system are meaningfully and consistently engaged.
2. **Principle 2: Make Data Available to Drive Decisions and Outcomes** | Mention is made of 'intermediary proxies' however, there is not specific language addressing the use of data by corporate, academic, or advocacy interests. Access and use of data by proxies such as corporate storage, aggregation, and analysis service-providers are oftentimes not sufficiently monitored, and this lax oversight will naturally lead to abuse.
3. **Principle 4: Promote Individual Data Access** | The draft appears to have excluded mention of consumer's indefinite physical control over their data and when such data is accessible to specific governmental and non-governmental entities. When use of identifiable data is permitted by consumers, they lack the ability to exercise line-level control over which practitioners or institutions may have access to their data.
4. **Principle 4: Promote Individual Data Access** | Providing fundamental education to all stakeholders, using culturally and language-appropriate means, is critical to lifting the entire community. To that end adding this or similar wording to Principle 4 seems appropriate: "... as well as a fundamental understanding of one's ideal and current health condition, the collection of one's diagnosis and care data, and a good understanding of both data and privacy concerns, how such data will be used, and protections empowering the consumer.

5. **Principle 5: Reinforce Individual Data Privacy & Security** | There is a concern about the principle point that would seek to "... reduce overly burdensome standards under the pretext of compliance to restrict the exchange (of) Health and Human Services (HHS) information." Naturally we want to reduce inappropriate barriers to utilizing data to lift the entire community. However, there seems to be a need to also communicate a counterbalancing effort made to ensure actions by this Exchange simultaneously seek to empower the community itself to strengthen and sustain consumer rights and protections.
6. **Principle 6: Establish Clear & Transparent Terms and Conditions for Data Collection, Exchange, and Use** | There is an apparent lack of ability for the ultimate arbiters of these principles to create or implement independent policy. The existing draft regularly defaults to the use of 'To the extent allowed by state and federal law.' used extensively throughout draft documents. However, such abilities provided to such an oversight body may prove valuable as legislators refine the law, which oftentimes takes years to actually codify.
7. **Principle 8: Accountability** | There is no mention of an oversight body other than "government organizations that oversee them" with the authority to control access to data by entities that may abuse privileges, or utilize economic penalties to deter potential abuse.
8. There is a lack of definitions of the terms and phrases used within the draft proposal. It is crucial key terms using a well understood nomenclature prevent misinterpretations.

If you have any questions or can direct me to the best method to contribute this feedback I would appreciate your response. I can be reached at:

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Thank you very much.

Reference

Data Exchange Is at the Heart of California's Drive for Health Equity, John O'Hanian 2/24/2022
<https://www.chcf.org/blog/data-exchange-is-heart-drive-health-equity/#related-links-and-downloads>

California Health & Human Services Agency Center for Data Insights and Innovation Data Exchange Framework Guiding Principles
https://www.chhs.ca.gov/wp-content/uploads/2022/02/CalHHS-DxF-Guiding-Principles_Final.pdf