



Privacy Standards and Security Safeguards:

https://www.cdii.ca.gov/wp-content/uploads/2023/08/CalHHS_Privacy-Standards-and-Security-Safeguards-PP_Draft_Aug-2023__For-Public-Comment_v2.pdf

September 18, 2023

Via email: CDII@chhs.ca.gov

Dear Mr. Ohanian,

We appreciate the opportunity to comment on the California Data Exchange Framework's Privacy Standards and Security Safeguard draft. We commend the State of California for taking steps to support data-driven efforts to better coordinate health and social services and provide opportunities to deliver services that are more client centered, efficient, effective, and tailored, and support the efforts to ensure interoperability across the state. After reviewing the Privacy Standards and Safety Safeguards draft policies & procedures, we would love an opportunity to meet to discuss these principles more in depth, and also greatly appreciate your initial commitment to a comprehensive privacy model that reflects the unique needs of both covered and non-covered entities.

Of particular interest to findhelp is how the DxF plans to support the privacy of non-covered entity generated data, such as the information generated by many diverse community-based social care organizations across California. Incorporating referrals to social care into our healthcare infrastructure relies on the collection, storing, and sharing of some of the most private and personal information. As California moves forward, it will be imperative that privacy is at the center of this conversation, with individuals maintaining control over how this information is shared.

Findhelp supports the privacy standards set forward in Section III Part 1, and concurs with your standards set forth on handling de-identification, non-covered entities, use of Business Associate Agreements (BAAs), and how Protected Health Information will be handled. To explicitly reiterate, findhelp encourages CDII to incorporate the following principles:

- Require a consumer-directed consent model, in which individuals are asked to opt-in to share their information to a transparently identified network or resource. Ensure social care network members' access to referral history is permission-based.
- Maintain the individual's right to obtain help without conditioning referrals on consent to share personal information.
- Require that individuals seeking help maintain the right to opt-out of sharing their information at any time, and ensure that revoking network access to personal information is simple for the individual.
- Allow HIPAA-covered entities to continue following existing pathways for sharing staff-generated referrals with Health Information Exchanges (HIEs) or other covered entities, pursuant to data sharing or network agreements.
- Prohibit the sale of personal information without explicit individual consent.

We would value a future conversation should you be open to discussing these more in depth, and we appreciate your leadership and work in California to streamline access to services and work towards interoperability and data-sharing as the standard.

In partnership,

Donna Cullinan

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findhelp, a Public Benefit Corporation

Submitted on behalf of findhelp, a Public Benefit Corporation.

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