



May 3, 2021

The Honorable Steve Glazer
California State Capitol, Room 5108
Sacramento, California 95814

**RE: SB 744 – As Amended 4/29/2021
OPPOSE UNLESS AMENDED**

Dear Senator Glazer:

The undersigned organizations are dedicated to protecting consumer privacy and must regrettably oppose your SB 744 unless it is amended. This bill provides for the expedited release of health care data to researchers at bona fide research institutions. We appreciate the amendments taken to ensure that individualized COVID information is not published publicly; however, the bill still lacks adequate guardrails to protect millions of Californians' sensitive personal information.

Current law requires state agencies, such as the California Department of Public Health (CDPH), to only release personal information for research purposes subject to the requirements of subdivision (t) of §1798.24 of the Civil Code (the IPA). Those provisions require, among other things, that (1) the disclosure occur only if the request for information is approved by the Committee for the Protection of Human Subjects (CPHS) for the California Health and Human Services Agency (CHHSA) or an institutional review board; (2) the researcher has provided a plan sufficient to protect personal information from improper use and disclosures; (3) the researcher has provided a sufficient plan to destroy or return all personal information as soon as it is no longer needed for the research project; and (4) access be given only to the minimum necessary personal information needed for the research project. These guardrails provide important privacy checks on the use and sharing of personal information collected by the state for one purpose and later shared for research purposes with a bona fide research institution of higher education.

SB 744, however, provides for expedited release of such information to qualified researchers who sign a memorandum of understanding (MOU) with the department. It is unclear whether this MOU is in addition to or in lieu of the process outlined in the IPA. Additionally, the bill is unclear whether "the department" refers to CDPH or would also include local health departments, which are not subject to the IPA. For these reasons, we request that the bill be amended to clarify (1) that the information may only be released by CDPH so that researchers

cannot bypass the IPA's important safeguards by requesting the same information from a local health department; and (2) that the release of information by CDPH to researchers is also subject to the requirements in the IPA. These amendments would also remedy a possible conflict with HIPAA,¹ which forbids release of this medical information without either patient consent or a determination by an Institutional Review Board, such as required under the IPA.

We appreciate the pressing need for reliable information while battling the ongoing COVID-19 emergency. However, Californians have a constitutional right to privacy, and it is vital that the state protect that right *especially* in this time of unprecedented crisis. Crises often open the door to erroneous judgment, panicked decisions, and programs that—while well-intentioned—undermine people's constitutional right to privacy and prove difficult to roll back. It is imperative that governments protect their people's rights when, as now, they are at their most vulnerable. To ensure that Californian's privacy is protected through this pandemic, SB 744 should be amended as suggested above.

Sincerely,

Emory Roane
Policy Counsel, Privacy Rights Clearinghouse

Lee Tien,
Senior Staff Attorney, Electronic Frontier Foundation

Tracy Rosenberg
Advocate, Oakland Privacy
Executive Director, Media Alliance

Susan Grant
Advocate, Consumer Federation of America

Becca Cramer-Mowder
Legislative Coordinator & Advocate, ACLU California Action

cc: Members and Staff of Senate Appropriations Committee

¹ <https://www.hhs.gov/hipaa/for-professionals/special-topics/research/index.html>.