From: Hamad, Rita <rhamad@hsph.harvard.edu>

Sent: Friday, November 8, 2024 12:06 PM **To:** CHHS CPHS < CPHS@chhs.ca.gov> **Subject:** Concerns re: new CPHS proposals

Dear CHHS Committee for the Protection of Human Subjects:

I write to provide public comment on the <u>latest draft</u> of the proposed regulations under the Information Practices Act.

My name is Dr. Rita Hamad, and I am an Associate Professor at the Harvard School of Public Health. My research focuses on the impact of social and economic policies (e.g., poverty alleviation policies) on health equity. To conduct my research, I rely on data collected by government agencies who then make that data available to researchers. Using that data, my research can thus make conclusions about the impacts of policies at the population level, and among high-risk subgroups who are difficult to sample in smaller research studies. This research directly informs state and federal policies to support health equity. For example, I have previously examined the impacts of safety net policies on birth outcomes using data from CPPH and OSHPD (now HCAI), providing valuable evidence to state and federal policymakers seeking to refine these policies.

I was concerned to learn that certain members of CPHS are pursuing regulations that could impinge on research using government-held data. Such data are at the core of modern public health and social science research. Critically, the Common Rule has long recognized that research using such pre-existing data sources should be afforded less scrutiny because it does not involve live contact with human subjects.

Instead, the new rules would go back and check the consent at the time of data collection, which contradicts how the Common Rule deals with pre-existing data. Many of these datasets have no initial consent (e.g., consent is not offered at birth in the creation of birth certificate data), which is why the Legislature has balanced the equities and put in place statutes that restrict the availability and use of such data for research. The CPHS should not – and don't have the authority to – substitute their own private views on privacy for those of our elected representatives. These new rules would also prevent researchers like myself from making concrete recommendations to improve the health of Californians, whose data would be under tighter lock and key than Americans in any other state. This would deprive vulnerable California populations of timely information on how best to improve their health. This would represent a major failure of CPHS.

I oppose the new regulations.

Sincerely,

Rita Hamad, MD, PhD

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