

From: Alisa Padon <apadon@phi.org>

Sent: Wednesday, March 5, 2025 4:00 PM

To: CHHS CPHS <CPHS@chhs.ca.gov>

Subject: Public comment on the proposed regulations under the IPA

I want to provide public comment on the latest draft of the proposed regulations under the Information Practices Act.

My name is Alisa Padon, and I am a research scientist at the Public Health Institute (PHI) based in Oakland, CA. My research examines the impact of state and local cannabis policy on the health and well-being of California residents to inform evidence-based policy to prevent harm to Californians and individuals across the U.S. We have a particular focus on children, pregnant people, individuals susceptible to psychosis, and cannabis dependence behaviors. State-level data, such as ED visits, are crucial for identifying the differential effects of cannabis policy on health.

I am also an IRB member at PHI, I was a senior administrator of the University of Pennsylvania IRB, and I have a master's degree in bioethics. I am deeply familiar with concerns related to confidentiality breaches and data reidentification. However, in my experience, the vast majority of researchers faithfully follow their duty to minimize these risks, and the benefits of the resulting findings align with both principles of beneficence and respect for persons.

If CPHS has a different experience, transparency of that record is crucial to justifying the proposed expansion of the committee's purview. The Proposed CPHS Fees document from 8/2/24 includes a table of the number of research requests in 2023 but lists no adverse events or unanticipated problems out of the 931 total actions the committee took in 2023.

Can CPHS compile and present a record of adverse events and/or unanticipated problems involving risks to persons or others involving confidential data exposures or unauthorized re-identifications that prompt its changes of review criteria and standards of approval? Please also include the proportion of these events within the total actions taken within a set period of time.

At this time, I recommend a vote in opposition to this proposal, or at a minimum, postponing such a vote until data describing clearly what problem is being addressed is publicly available to the affected community of researchers and examined.

I appreciate your consideration.

Sincerely,

Alisa Padon

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