

From: Eric McGhee <mcghee@ppic.org>
Sent: Thursday, October 3, 2024 9:03 PM
To: CHHS CPHS <CPHS@chhs.ca.gov>
Subject: proposed changes to human subjects review

Dear CHHS Committee for the Protection of Human Subjects:

I write to provide public comment on the [latest draft](#) of the proposed regulations under the Information Practices Act.

My name is Eric McGhee and I am a Policy Director and Senior Fellow at the Public Policy Institute of California. I study a range of topics, including demography, housing, and elections and voter turnout. My research aims to identify policy options that will promote prosperity, opportunity, and democratic participation for all Californians.

To conduct my research, I rely on data collected by government agencies who then make that data available to researchers. 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 social-science research and 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 (eg, consent is not offered at birth), 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.

I do not oppose the careful protection of privacy in administrative data. We must always consider the benefits and costs of any research project and ensure that it is conducted with the privacy of subjects foremost in mind. But when it comes to administrative data, the primary risk comes from disclosure itself, whether or not the data have been merged with other sources of information. That is why personally identifiable information almost never leaves the government agency in possession of it, and if it does, it is always under strict restrictions surrounding its storage and use. The additional risk of research using administrative data is therefore manageable and typically greatly outweighed by the benefit of informed and intelligent public policy.

We should focus on ensuring confidentiality, not burdening useful research under the weight of restrictions that would provide little benefit to justify the cost.

I oppose the new regulations.

Sincerely,

Eric McGhee
Senior Fellow

PUBLIC POLICY
INSTITUTE OF CALIFORNIA
500 Washington Street, Suite 600
San Francisco, CA 94111
tel 415 291 4439
fax 415 291 4401
web www.ppic.org

Any opinions expressed in this message are those of the author alone and do not necessarily reflect any position of the Public Policy Institute of California.