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March 27, 2020

Mr. Xavier Becerra

California Department of Justice

ATTN: Privacy Regulations Coordinator

300 S. Spring Street, First Floor

Los Angeles, CA 90013

By Email to: PrivacyRegulations@doj.ca.gov

**Re: Revised CCPA Proposed Regulations**

Dear Attorney General Becerra,

The International Pharmaceutical & Medical Device Privacy Consortium (“IPMPC”) welcomes the opportunity to provide comments on the revised proposed regulations under the California Consumer Privacy Act (CCPA).

The IPMPC is comprised of chief privacy officers and other data privacy and security professionals from a number of research-based, global pharmaceutical companies and medical device manufacturers.[[1]](#footnote-1) The IPMPC is the leading voice in the global pharmaceutical and medical device industries to advance innovative privacy solutions to protect patients, enhance healthcare, and support business enablement.[[2]](#footnote-2)

The IPMPC appreciates the revisions made by the Attorney General to the first and second drafts of the CCPA regulations. The changes in the third draft provide additional clarity to businesses, but contribute to uncertainty by removing key guidance. The IPMPC also wishes to reiterate its previous requests that the Attorney General clarify important aspects of the draft regulations. In particular, the IPMPC wishes to call the Attorney General’s attention to its previous comments on §§ \_.301(c); \_.305(a)(3); \_.306(e); \_.313(d)(3); \_.314(c); \_.314(e); and \_.317(g)(2). A copy of each of our previously submitted comments are attached as appendices for ease of review.

Further, the IPMPC reiterates its request from our initial and second set of comments: We ask that the Attorney General publish examples of the various notices and responses to consumer requests that would be required under the proposed regulations. Example materials will greatly assist businesses in crafting compliance materials that meet consumer expectations under the CCPA.

§ \_.302 The IPMPC believes the previous interpretative guidance on the definition of “personal information” provided by the Attorney General in this section should be restored. As the IPMPC noted in its February comments, that interpretative guidance offered needed clarity about the standard to be applied when determining whether data held by a business is “personal information.”

As noted in prior comments, in many cases, IPMPC members collect data for medical or scientific research that includes information that member companies do not and could not link with a specific person. For example, an IPMPC member company might be engaged in epidemiological research to understand the scope and course of a rapidly emerging and spreading disease. To better understand where the condition has originated and how it is being treated, an IPMPC member company might partner with a public health or health care organization that has data about patient experiences and outcomes. To conduct its research and consistent with the ethical guidelines applicable in these scenarios, the IPMPC member would not receive this data in a reasonably identifiable format. However, the data may contain information which appears on the list of data elements included in the definition of “personal information” under the CCPA “if it identifies, relates to, describes, is reasonably capable of being associated with, or could be reasonably linked, directly or indirectly, with a particular consumer or household.” IPMPC members need clarity about how such data elements should be treated where they are not reasonably identifiable but could possibly be viewed as “relating to” “particular” individuals. The removal of the Attorney General’s interpretative statements creates uncertainty and confusion around an important issue affecting research relevant to the health and well-being of Californians.

As noted before, the IPMPC believes that a clarifying statement about what information should be considered either deidentified or not personal information would be helpful. The IPMPC continues to urge the Attorney General to make it clear that information which has been deidentified using a process described in federal regulations (like the HIPAA deidentification standards) will be considered deidentified for the purposes of the CCPA.

§ \_.308(c) In both § 999.308(c)(1)(d) and (2)(d), the proposed regulations call for the inclusion of a “general” description of the verification process that will be used when a consumer seeks to exercise their rights. However, the verification process used may vary significantly depending on who the consumer is, what information the business has about the consumer, the nature of the relationship between the business and consumer, and the standard that needs to be satisfied to “verify” the consumer based on the data possessed by the business. The IPMPC believes that even with the addition of the modifier “general,” the requirement to describe the process used to verify the consumer presents significant practical challenges. For example, verifying the identity of a patient-support program participant, where a member company may have repeated interactions over a period of years and the data includes sensitive health information, will follow a different process than verifying the identity of a consumer who signed up for a mailing list, but otherwise has no interaction with the company.

Consumers should be informed that there will be a verification process, but providing a description of that process that applies to all consumers will require either the use of unhelpful generic statements or presenting descriptions of several possible processes, most of which the consumer will not encounter. At a minimum, the requirement to describe the process should be moved to the first response to the consumer acknowledging their request, at which point the business may have a better idea of the nature of the process that will be required for that consumer.

§ \_.313(c)(3) The IPMPC continues to urge the Attorney General to reconsider the deletion of text from the original draft regulations that occurred in the February draft. This text was not restored in the most recent draft. The IPMPC previously commented on this deletion but wishes to reiterate that the Attorney General would best serve Californians by more explicitly permitting businesses to withhold information when disclosure would put other consumer’s personal information or the business itself at risk. The initial draft of the regulations appropriately provided further clarity around Civil Code 1790.145(l). The current draft of the regulations creates unnecessary uncertainty as to whether a business is permitted to decline to disclose information to consumers when it reasonably believes that disclosure creates a risk of harm for other consumers or the business’s employees—for example, where disclosure of negative profile information might cause retaliation or harassment. Such a standard is reasonable and consistent with other privacy and data protection regimes.

§ \_.313(d)(7) The IPMPC opposes the requirement to offer unverified consumers the option of opting out of the sale of information. In many instances where verification cannot occur, the business will also lack the necessary information to implement an effective opt-out. Requiring that the business offer an opt-out it could not deliver would lead to consumer frustration without delivering tangible benefit to consumers.

§ \_.317(e) The IPMPC appreciates that the Attorney General revised the restriction on sharing record-keeping information with third parties to explicitly acknowledge that such information may be shared where required by law. Nevertheless, we reiterate our previous request that the Attorney General also make it clear that the information may be shared when an exception to the CCPA applies—like in the course of defending a legal claim or when exercising an evidentiary privilege.

We thank you for the opportunity to provide these comments.

Sincerely,



Peter A. Blenkinsop

IPMPC Secretariat

Appendix 1:

IPMPC Comments on Initial Proposed Regulations

Appendix 2:

IPMPC Comments on First Modifications to Proposed Regulations

1. IPMPC members may also operate related businesses, including in vitro diagnostics manufacturing and CLIA laboratories. [↑](#footnote-ref-1)
2. More information about IPMPC is available at https://www.ipmpc.org/. This filing reflects the position of the IPMPC as an organization and should not be construed to reflect the positions of any individual member. [↑](#footnote-ref-2)