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Department of Health Policy and Management

June 6, 2021

Harvey Perlman
Chair, Drafting Committee
Collection and Use of Personally Identifiable Data Act
Uniform Law Commission
111 N. Wabash Ave., Suite 1010
Chicago, IL 60602

RE: Comment on the Draft Uniform Personal Data Protection Act

Dear Chairman Perlman,

Thank you for this opportunity to provide a comment on the Uniform Personal Data Protection Act (UPDPA). We are professors at Texas A&M University speaking in our capacity as scholars in law, data protection, and data science. Previously at the Centers for Disease Control and Prevention and now in academia, Cason Schmit has worked with state, territorial, local, and tribal partners and non-profit organizations to navigate the legal barriers to using data for public health purposes. As a data scientist, Dr. Hye-Chung Kum has extensive experience negotiating data access permissions with data controllers, leveraging large datasets to better understand health outcomes and handling sensitive personal data to meet privacy standards. Dr. Brian Larson has published on First Amendment dimensions of public records and privacy and on similar aspects of online agreements, which often implicate privacy concerns. We applaud the Committee's efforts to simplify the US data protection framework by developing this model legislation that will contribute to more uniform data protection rules with adoption by state governments. We would like to propose one substantive change to the UPDPA. We strongly encourage the inclusion of an express provision for public health use as a compatible practice under Section 7. Below we detail our rationale for the suggested revisions.

The current draft of the UPDPA does not include explicit language that permits disclosures of personal data for public health purposes. Forthcoming research shows that public health data uses are exceptionally popular among the US public.[1] Unfortunately, exceptions to privacy laws and policies for public health are rare.[2,3] The absence of express authority to use personal data for public health leads to tremendous harm. For example, the 42 C.F.R. Part 2 regulations that protect substance abuse treatment information lack an exception for data use for public health purposes. Without this data use exception, the law has been a substantial barrier in the response to the ongoing opioid epidemic still ravaging the country.[4]

Moreover, many non-health data sources have public health significance, which supports the inclusion of a broad public health exception. Many non-physiological and non-biological factors can have a tremendous impact on a person's health, and these social determinants of health are estimated to kill as many people annually as leading causes of death.[5] For example, low education is estimated to kill as many people annually as heart attacks.[5] However, many current laws do not permit leveraging these data for public health purposes.

Revising the UPDPA to include data processing for public health as a "compatible data practice" would reverse the current backward approach of many US privacy laws. Research shows that the US public is far more comfortable with uses of data for public health than many other common data practices.[1] Specifically, a representative survey of 504 US adults showed that use of education data for public health purposes was the most popular of 72 data use scenarios.[1] The least popular was using economic data for profit-driven purposes. Consequently, making data processing for public health a "compatible data practice" would bring the UPDPA in line with public preferences and enable activities promoting substantial social benefit.

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The Section 7(a)(6) factor that allows data processors to weigh data subjects' economic, health or other benefit is insufficient for public health data uses because it focuses on the specific data subject rather than the broader population. When determining whether something causes poor health—or promotes good health—data processors need data from both those who are and are not affected. Like a clinical trial control group, data processors need to see that the factor under investigation affects those individuals who are exposed to the factor compared to those individuals who are not exposed to the factor. A given public health data use will certainly benefit some data subjects' economic, health or other interests directly, but other data subjects (i.e., the control group) may only receive an indirect benefit, if any. Nevertheless, defining data processing for public health as a compatible data practice will collectively benefit entire populations.

Similarly, the provision permitting data use for research in Section 7(b)(6) likely will not cover public health activities. There has long been a legal distinction between public health activities and research. This distinction is defined into major federal data protection regulations including the Health Insurance Portability and Accountability Act and the Common Rule protections for human subjects research.[6,7] As a consequence, public health authorities have existing processes to determine whether a specific activity qualifies as public health practice or research for compliance purposes.[8] A separate exception permitting data use for public health purposes would permit traditional public health activities that would not be covered by the research provisions in Section 7(b)(6).

Accordingly, we suggest the Committee adopt language to make data processing for public health purposes a compatible data practice. Specifically, we propose adding a paragraph to Section 7(b) stating:

"*permits analysis for preventing disease, prolonging life, and promoting health of communities in the public interest*."

With regards,

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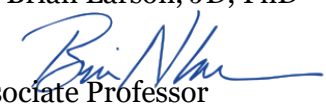

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