

patientprivacyrights

October 16, 2020

Mr. Harvey Perlman

Chair, ULC Collection and Use of Personally Identifiable Data Committee Nebraska College of Law

McCullum Hall (LAW) 263

Lincoln, NE 68583-0902

Dear Mr. Perlman,

Patient Privacy Rights Foundation agrees with the points made in the analysis submitted by Consumer Reports, Common Sense Media, Consumer Federation of America, Electronic Frontier Foundation, and Privacy Rights Clearinghouse and we concur that “The October discussion draft moves further away from this premise towards enshrining an unacceptable status quo.”

Although it is tempting to promote innovation by minimizing regulation in favor of industry self-regulation, the Committee should recognize that only works if there is adequate transparency and enforcement. For example, in 2003, HIPAA took away the patient’s right to consent in an unfortunate compromise that introduced an Accounting of Disclosures as a way for patients to understand how data is being used. Industry either ignored the transparency provision or made it inaccessible. Has anyone ever seen an accounting of disclosures of their health data? Has there ever been enforcement of this aspect of HIPAA?

17 years later, computers and networks are fast and reliable enough to allow our services to contact us contemporaneously for a \$0.99 music purchase if they choose. Logs of transactions are easily accessible online to each of us with online access if a service chooses.

Transparency of personal data uses, regardless of the pretense of anonymity, pseudonymity, blending with “public information” and other means to avoid informed consent for data use, needs to be the floor for any privacy regulation design. It is only through transparency that our legal and business practices can be provided with the essential feedback lawmakers and citizens need to protect both individual and societal interests.

The October Draft is a move in the wrong direction.

Sincerely,

Adrian Gropper, MD
CTO, Patient Privacy Rights

Deborah C. Peel, MD
Founder and President, Patient Privacy Rights