

Oregon Legislature

SB 703 Hearing Public Hearing

Personal Testimony of Milind Kamkolkar, Citizen

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Chairman Prozanski, members of the Committee,

Thank you for the opportunity to share my views with you today from the perspective of a senior executive in the biopharma industry.

I am Milind Kamkolkar, a resident of New Jersey, a seasoned biopharma executive having worked in both start up and big pharma. My career has spanned across building large scale data and analytics initiatives in the Life Sciences industries from R&D to commercialization of products we see today. I have run hackathons with patient communities with a specific focus on improving the engagement between physicians and patients where the ecosystem around that important relationship, has to remove barriers to access to information whilst doubling down on providing value added services leveraging digital and data as its cornerstone capability.

As such, the rights of patients and the utility of data by the ecosystem is something I have deep experience in as well as practical implementations of how to get this done.

It is for this reason, I applaud this committee on bringing this Bill, the first of its kind in the Nation, to the Legislature on behalf of the Citizens of Oregon firstly, BUT should it get approved, will draw upon the nation a differentiator in the world economy as it pertains to citizen owned data. Bottom line, this a crucial step for the US to take lead in what will be an international requirement.

I have been involved in data purchasing agreements, data transfer agreements, data generation agreements and in all my time, I can count on my fingers the number of times I could truly answer with certainty, "was this data procured/generated under a mechanism in which the patient, who so graciously signed the consent form, knew how it was being used?" Rather, the agreements in themselves were more defined by legal language designed to support liability than creating value.

Frankly, we have seen enough evidence of data breaches in this industry and many more where one must ask the question: how many breaches are we willing to endure before we hold companies and organizations accountable for the mishandling of our personal data, and specifically our Healthcare data?

Consider the scenario of a diabetic patient, a horrific ailment that impacts the heart, breathing, weight, self-confidence and mental health. Now imagine having to go to a primary care, nephrologist, dietician, cardiologist, diabetics specialist, pulmonologist and therapist. All these good folks are ordering multiple, repetitive tests but just because they are looking at the data in their own way, they exist in silos for the patient. Allowing patients to OWN this data as their property drives a more comprehensive adjudication of disease a treatment strategy, that should a patient want to share this data for research purposes, can do so with a remuneration that is commensurate with the amount and quality of data produced.

Let me be very clear about this: Nobody has the right to sell or broker my health data – anonymized or not – without my specific, expressed permission. Current consent forms do not do enough to protect my data. That is VERY clear.

Biopharma companies would benefit immensely from ethically procured data and will enable a more relevant relationship with patients to provide them greater access to what their data means in the context of treatment. In fact, physicians would be key drivers in this more trusted relationship. Today, much of the pharma industry is in the dark beyond legal documents as to this process documented by data aggregators that it's now wonder why lack of trust exists in the industry.

I'd like to echo the note that implicit in the spirit and intent of HIPAA, is the belief that the patient owns their own data, meaning it is their property. SB703 explicitly addresses and provides for this.

Finally, while I am a biopharma executive and understand many of the positions you will hear expressed in opposition to this bill, this is not a technology issue (echoed by digital/tech companies that aggregate data), this is not a business model issue (biopharma has to change and this helps them not impede) – I also see this more as a Civil Rights issue.

Our National and State constitutions define and protect our civil rights, including our property rights. Throughout our history, we've passed legislation, legislation that in hindsight can be declared landmark legislation, recognizing and protecting our civil rights.

Again, thank you for your time and for the opportunity to be heard.

Sincerely,
Milind Kamkolkar, Chief Data Officer