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Chairman Prozanski, and members of the Committee, thank you for the opportunity to speak with you today about the opportunity for SB703 to lead the nation in a reconceptualization of how we treat data. In doing so, you will serve to accomplish two major goals.

First you will recognize the fundamental right for people to own and control as their property the data that describes them; and second you will improve the ability of researchers to gather essential insights about illness and wellness, allowing us to better diagnose and treat devastating diseases.

If I impress upon you only one thing in these few minutes I am before you today, it is this: these two goals are not mutually exclusive, nor are they in opposition to one another. In fact, they are complementary, and perfectly aligned. In realizing them, you will allow human rights, medicine, and science to move forward in lock step for the betterment of all people.

To help elucidate how this can be the case, I want to tell you how I understand the problems and solutions in the space. I am a physician who actively treats psychiatric illness and addiction, a researcher working on academic projects, and have worked inside of and in support of pharmaceutical and medical device research.

In research, data acquired from the routine practice of medicine differentiate from data collected in the course of clinical studies. The data we're talking about today are generally those that are collected in the course of routine care, your annual checkup, an emergency visit after an accident, or treatment for chronic disease. These data, when used for research, have been called real world data. When this information is used to generate insights about medicine or medical care, we sometimes call them real world evidence. Data that emerges from controlled clinical studies has always been more easily translated into meaningful information because the data are cleaner, the situation in which they were collected is controlled, and studies are designed to reveal very specific pieces of information.

Real world data on the other hand are generated for purposes other than research. They are generated in the course of routine care and routine life. They are everything from your lab values, to your x-rays, to the notes that your nurses and doctors write to describe what they observe about you and the choices that they make for treatment. Because these data are collected for the purpose of documenting care, of protecting against liability, and for billing, they are not particularly well organized or suited for use in research.

As we've discussed, a new industry has emerged to repackage and resell these data for research. However, despite extensive effort in this ecosystem, these data have not led to nearly the impact that we had all hoped as we entered this era. Simply put: despite the computerization of medicine and extensive assimilation of data, the value of real-world data is not reaching anywhere near its full potential.

Opponents of this bill will tell you two things related to the use of these data in research. They will say that the data in their current form are working for researchers, and they will say that this bill or others like it will staunch the flow of data to researchers, thereby impeding our ability to generate new insights.

I must tell you that both of these arguments, while convenient for the folks who profit on selling this data, are wrong. Real world data, as they currently exist, are most useful for understanding financial patterns or healthcare on larger population levels. These broad strokes may describe behaviors state by state, sometimes county by county, but not much more than that. This is due to the fact that these data are not intrinsically well suited for research, in part because they must be deidentified for unconsented resale. It has been said before, but it is at the core of this issue to understand that de-identification, as described in HIPAA, while well intentioned, in the modern data environment does not meet its intended goal. De-identification does not prevent malevolent entities from re-identifying data but it does prevent well intentioned researchers from making good use of the data.

While de-identification is a handy shield for data brokers that allows for the legal resale of data, it bears repeating that it does not protect patients and it obstructs useful research. I have worked with these data as an academic researcher and as an employee of a major pharmaceutical company. While the real-world data were useful for marketing and projecting revenues, they provided little to no value in generating insights that enabled the discovery or development of new medicines. We are facing epidemics of illnesses for which no effective treatment exists. We are unable to modify the course of terrifying illnesses such as Alzheimer's and Parkinson's disease, and the current state of real-world data isn't getting us any closer.

There is an alternative and it is enabled by human ownership of data. Rather than accepting that the best we can do is de-identification, we propose a system whereby individuals can participate in the exchange of their own data. Where the data are high quality and ethically obtained, and where the people who are the source of the data are able to continue to contribute to the search for medical knowledge that their data is contributing to. Data ownership allows for individuals to consent to the integration of their data across multiple sources, enabling increasingly powerful research questions to be asked of the data and better medicines to emerge as a result.

I am here because I believe that the current state of medical data is ethically broken and it is scientifically broken. We have, through the evolution of the medical data business, managed to end up with the worst of both worlds. In the discovery, development, and delivery of new treatments, we have enormous challenges ahead of us. These challenges require a new way of regarding medical data. SB703 is an opportunity to set a national precedent for a way forward that repairs the ethically indefensible current practices by bringing the individual and their consent back into this process, and takes a huge step in the direction of maximizing the scientific value of medical data, mitigating preventable death and suffering and offering the greatest chance for maximizing human health and wellness through research.