



## **Oregon Legislature**

SB 703 Public Hearing

Personal Testimony of Austin Jones, Chief Executive Officer, Unity Health Score

February 19<sup>th</sup>, 2019

Chairman Prozanski, members of the committee, on behalf of Unity Health Score, I would like to thank you for bringing this Bill that could help alter the future of humanity similar to the printing press, the assembly line, and the internet.

I am Austin Jones, Humanitarian, Entrepreneur, Founder, and CEO of Unity Health Score. I started Unity Health Score after witnessing first hand how difficult it was for patient's to navigate our fragmented healthcare system, having been the main caregiver for my grandmother with dementia, Joanne Jones. In providing in-home care for her for nearly a decade and directing her medical visits and communication with various specialists, I found a lot of problems in healthcare, most of which centralize down to one point and that's the lack of transparency.

There are many points where patients not having control of all their medical data leads to lack of transparency. Risk modeling, where health insurance companies determine how much a patient might "cost", only utilize a small part of a person's health data to identify high-cost patients, while giving those patients no comprehensive analysis of their risk scores, and no ability to change them. We believe people need to be competent in what their data indicates about them, and be comprehensively informed as to who is using their data, and how it's affecting them. This Bill would be a positive first step that will help create a pathway for deeper transparency initiatives like Unity Health Score to make an impact on a currently opaque risk modeling process. Once people can be compensated for their health data, they will put forth the effort required to collect it and make it more complete, and be more willing to share it for reasons that impact both their health and their wallet.

Another reason we need to motivate people to collect and share their health data is because when doctors don't have access to it, medication changes between various specialists can cause great harm when medicines conflict. Multiple occasions have occurred where my Grandmother's Cardiologist has prescribed medications that conflict with her current ones, only to find out days or weeks after they've been prescribed. This issue isn't a conflict between our Primary Care Provider and Cardiologist; this is our professional care providers not being able to do their jobs because data isn't readily accessible for the patient's treatment. It's stored and siloed to maximize profits for health systems, electronic health record (EHR) vendors, and the companies that broker "anonymized" data on their behalf.

Brokers generally don't care how the data is used, or what negative impact it might have on the people who create it. Medical records continuously wind up on the black market, and illegal activity from broker-purchased data is a serious problem with no regulatory safeguards in place to prevent their occurrence. I personally know that scammers identify older people with dementia as vulnerable targets, as my Grandmother got scammed out of her and my Grandfather's entire life savings in 2012. HIPAA "de-identification" for disclosures of medical data fails us as there's no regulations that prevent others from re-identifying the data through cross referencing and propensity modeling.

Unity Health Score, Inc.

4085 Rocky Drive, Niceville, Florida 32578

Phone: 850-865-5229 / Email: [contactus@unityhealthscore.com](mailto:contactus@unityhealthscore.com)



The data trade is the 21<sup>st</sup> century gold rush - the information market that fuels our innovative growth - but right now, many people are being hurt by it. Personal data ownership is the difference between a literate and illiterate society in this age of information. Additionally, personal data ownership will become a safeguard against dangerous artificial intelligence that many like Bill Gates, Elon Musk, and Stephen Hawking have campaigned for humans to prioritize. Further, analytics that use incomplete, cold-sourced data are already impacting people's lives in a negative way. But the potential value and utility that can be created when people own and control their health data is abundant. While the traditional job market dries up from automation, and analytics continues to destroy any hope for our privacy, the mechanisms this Bill seeks to put in place could change that narrative in the State of Oregon and beyond. Are we going to allow for the interests of old business and big money to shape our laws, creating a future where many are hurt by the lack of transparency with their own data? Or are we going to build a world where there's a form a basic universal income through personal data ownership that can combat homelessness and poverty?

Personally, I'm not waiting. I designed a company that offers a transparent alternative to risk modeling for health insurance that empowers people with their data and aligns incentives to produce interoperable medical profiles. We need to make patients aware of what's wrong with them to enable them to reduce their costs by getting healthier, instead of abusing the lack of transparency and preying on the sick because it's "better for the bottom line". SB 703 is nothing less than a better, more transparent vision for the future of our society. It's the initial stepping stone in creating a future-proof economy that promotes efficiency and ethics over profits and personal gain.

We support the passing of SB 703, and commend this committee for bringing on a Bill that will set the pace for a better, more transparent future. I'm truly honored to have had the opportunity to make Unity Health Score's voice heard during this monumental hearing.

Thank you,

Austin Jones  
Founder & CEO  
Unity Health Score