

Oregon Legislature

SB 703 Public Hearing

Personal Testimony of Matt Sinderbrand, MPH

CEO of Betterpath, Inc.

February 19, 2019

Chairman Prozanski, members of the Committee, on behalf of Betterpath, Inc., I'd like to thank you for the opportunity to share our views with you today.

I am Matt Sinderbrand, a citizen of the State of Colorado, an information technologist, a data privacy expert, and co-founder and CEO of Betterpath. I've spent my entire professional career helping patients collect, control and share their lifetime medical records, and co-founded Betterpath in 2012 as a way to further this goal. After experiencing the opposite of "evidence-based medicine" first-hand in my own family, we made it our mission to use the data in these medical records to figure out how different treatments affect different people with the same chronic disease. The knowledge and wisdom we've accumulated through the tireless pursuit of this goal has guided our position on the matters in this Bill.

Prior to serving as CEO, I operated as the company's HIPAA Compliance Officer, and was a key contributor to our data science and research initiatives. My exposure to the nuances of both privacy legislation and medical research have provided me with unique perspectives that are highly relevant to the discussion at hand.

Rather than focusing on the social benefits that such a landmark Bill would introduce, I'd like to focus explicitly on why we at Betterpath believe that the proposed legislation has far broader financial implications for the health system at large, and how the mechanisms it puts in place will lead to a healthcare delivery system that provides better care for patients at a lower cost.

The financial implications of this Bill, both for individuals and the health system at large, cannot be overstated. Even though legislative mandates currently require healthcare providers to share patient data electronically, the fact is that large health institutions will continue to silo their data because they earn revenue from it, and they will fight tooth-and-nail to protect this revenue source. The "business-side" of healthcare doesn't care that our health system is broken, evidenced by the fact that medical errors are the 3rd leading cause of death in the U.S. ([BMJ, 2016](#)). After 7 years of painstaking investigation, we at Betterpath believe the most significant factor contributing to this sobering statistic is the fact that doctors *cannot* access a complete set of health data for *any* patient, regardless of the care setting. This lack of access to complete medical histories is also a key contributor to the \$1T waste problem in healthcare, as it leads to widespread duplicitous testing and ineffective treatment decisions.

The only stakeholder in the health system with the legal right to access a complete set of health data is the individual patient, but if you've ever tried to get a copy of your medical records from a hospital, you know that the process is such a pain that most of us only do it when absolutely necessary. By compensating consumers for the access and use of their health data, this Bill will motivate people to "do the job" of collecting, maintaining and *improving* the completeness of their health data *as a financial asset*. In our view, complete patient-controlled health records are a crucial first step toward achieving the Institute for

Healthcare Improvement's (IHI) "Triple Aim" of enhancing the care experience, reducing per-capita costs, and improving the health of populations, as well as the goals of the Institute of Medicine's (IOM) "Learning Health System". To achieve these visions for a better system and move healthcare into the 21st century, we need complete medical records.

To address some of the opposition to this Bill - nothing that I've read would in any way impact a doctor's ability to access the patient data needed to provide care, nor would it impact a researchers ability to access data for clinical or academic studies. Current federal privacy legislation like HIPAA clearly protects these "covered entities" rights to access data for these purposes, but it also establishes the need to obtain the patient's consent for any disclosure of health data that is not designated for treatment, payment or *healthcare operations*.

While the *healthcare operations* designation under HIPAA is meant to help researchers and administrators access data to improve certain aspects of the healthcare system, it has also created the loophole that enables the blatant sale and resale of "anonymized" health data. It's becoming apparent to many, as it has been to those of us working in data privacy for some time, that there is *no such thing* as a fully de-identified or "anonymized" set of data, yet 3rd party data brokers - some of which are here today - exploit this provision in the law to the tune of \$70B+ each year. We believe the demand for transparent accounting of such disclosures will soon reach a fever-pitch, and that this Bill would set the stage for the "data ownership debate" to move into the national spotlight.

We believe that Betterpath, and other solutions that enable patients to control their health data, will add a valuable element of transparency sorely lacking in healthcare, and lead to a more trustworthy relationship between patients and healthcare organizations, ultimately leading to better health outcomes. But after spending seven years building technologies to reform a broken health system, we can confidently say that barriers to reformation are not at all technical in nature - they are fundamentally rooted in people's behavior. This Bill would be a transformative first step toward a health system that's truly centered around the patient, and more importantly, create a tangible incentive for consumers to care about their health.

Betterpath applauds this committee for bringing on this Bill to the Legislature, and wholeheartedly supports its passing.

With gratitude,

A handwritten signature in black ink, appearing to read 'Matt Sinderbrand'.

Matt Sinderbrand

Co-founder and CEO, Betterpath, Inc.