



**Testimony of Kimberly McCullough, Policy Director  
In Opposition to SB 703  
Senate Judiciary Committee  
February 19, 2019**

Chair Prozanski and Members of the Committee:

The American Civil Liberties Union of Oregon<sup>1</sup> opposes SB 703, which aims to reframe privacy as a property right in the context of health data.

At the outset, we want to acknowledge that there are numerous sponsors of this bill who we have worked with on privacy legislation throughout the years. We commend each of these sponsors for being advocates for privacy in Oregon, and we hope to partner with them on privacy legislation moving forward. We also want to make clear that we appreciate the fact that this bill is a conversation starter about the need to look closely at our laws relating to health privacy. And we can understand why it may have been intriguing to the bill's sponsors. It is quite novel and interesting in its approach.

**That said, we believe this bill is something like a Trojan Horse.** On its face, this bill is being promoted as a privacy and transparency bill. We are convinced that it is something quite different. At best, problematic and unintended consequences sit beneath the surface of an otherwise well-intentioned policy proposal. At worst, this bill and others like it are a profit-making scheme.

To be clear, taking the entity that asked for this bill to be introduced at their word, their motives are altruistic. We are not here to question them on that point. At the same time, we are seeing similar bills and concepts pop up around the country, promoted by a burgeoning industry of for-profit companies that are in the business of *motivating people to sell their health information*. That gives us great pause.

We hope it will give you pause too, so we can have a longer conversation about health data privacy and dive deeper into exactly what this new "reframing" of privacy would and could do to our rights.

**We are told this bill will promote privacy, but we are deeply concerned that it instead threatens it.**

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<sup>1</sup> The American Civil Liberties Union of Oregon (ACLU of Oregon) is a nonpartisan, nonprofit organization dedicated to preservation and enhancement of civil liberties and civil rights, with more than 45,000 members and supporters statewide.

**First, we believe this new framework for privacy would create a new and powerful incentive for people to sell even more of their privacy than is currently being transmitted.<sup>2</sup>**

It does this by creating a system where consumers face a choice:

- Get paid nothing and maintain your privacy;
- Get paid something if you give away de-identified data; or
- Get paid more if you give away even larger sets of personal health information.

In conversations about this bill, we've heard there are studies that show people are not motivated by money in this context. We find this claim dubious.

We also find it interesting that numerous for-profit companies that have submitted testimony in support of this bill have praised it by pointing specifically to the fact that people will be given a financial incentive to share *more* of their personal health information, because of the property model and payment system this bill creates.

**Second, we fear this will create a two-tiered system of privacy.** Depending on a person's financial circumstances, their motivations and the incentive system created by this bill will operate differently. We already face a digital divide<sup>3</sup> in many ways. This new framework threatens to create another.

**Finally, we are deeply concerned by how this may impact our constitutional right to privacy,** which we believe could be completely undermined by a shift to a property model of this type. Time and research is needed to truly understand the breadth and depth of this danger to our constitutional right to privacy, but our initial response is frankly one of alarm.

**There is danger of a profit motive operating here in problematic ways, both as it relates to the very creation of this reframing of privacy and the way it could play out.**

**Industries do not simply spring up where there is no money to be made, yet that is happening here.** There is a reason that a budding industry is calling for this new framework that would enable them to grow a new business model and a new market.

**First, there's the technology that would be needed to track the authorization and sale of data.** Without a system in place to track authorizations and sales, the system would be unmanageable and data transfers would come to a grinding halt. But that is not the plan.

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<sup>2</sup> Relevant article from TechCrunch: <https://techcrunch.com/2018/07/18/hu-manity-wants-to-create-a-health-data-marketplace-with-help-from-blockchain/> (This article describes how this new framework will encourage people to sell identifiable data in addition to de-identified data, resulting in more data (in quantity and type) being sold.

<sup>3</sup> A digital divide is an economic and social inequality in the access to, use of, or impact of information and communication technologies. See [https://en.wikipedia.org/wiki/Digital\\_divide](https://en.wikipedia.org/wiki/Digital_divide).

In fact, the new industry that is promoting this model has not stated any intention to stop or even slow the flow of information. Quite the contrary. Where this bill and other policies like it would create a barrier to the flow of information, the industry that supports this new framework happens to have developed platforms (including phone applications) to track authorizations and sales.

**Second, this new framework necessitates the negotiation of data sales through the entities that have created these new platforms, with those entities taking a cut of the sales.<sup>4</sup>**

In simple terms, this would be adding yet another layer of data brokers to our existing system. It also raises even more questions:

- Who sets the price of these sales? Is it the patient or these new data brokers?
- How big of a cut of sales does the data broker receive?
- What ensures that there will be fairness and transparency in these negotiations?
- Once a sale has taken place, how do we really know that data will not face the same system insecurities that have been identified in the current scheme?

**Finally, the promotion of this new framework is not going to stop here.** Numerous companies are building a new business model based on how this framework could apply to various types of data, from financial data to geolocation data and more.<sup>5</sup> Even the founders of Hu-manity.co have publicly acknowledged an intention to reach other data markets with this new model.<sup>6</sup>

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<sup>4</sup> Relevant article from NPR: <https://www.npr.org/sections/health-shots/2018/10/15/657493767/if-your-medical-information-becomes-a-moneymaker-could-you-could-get-a-cut> ("Pharmaceutical companies could potentially pay each user \$10 a month for access to their data, Etwaru says. **The drug companies would also pay Hu-manity.co for access to these preferences.** Hu-manity.co is framing its for-profit business as a fight for a new human right.").

<sup>5</sup> Relevant article from Market Watch: <https://www.marketwatch.com/story/americans-data-is-worth-billions-and-you-soon-might-be-able-to-get-a-cut-of-it-2018-10-09> ("People are beginning to realize that everything they do is tracked," Budzyn said. "People are starting to realize they are valuable, and some are starting to consent, saying '**I don't mind if companies sell me; I just want a piece of it.**'").

<sup>6</sup> Relevant article from Medium: <https://medium.com/neodotlife/hu-manity-richie-etwaru-data-as-property-7986077d4d4b> ("[The founder of Hu-manity.co] seems to be sincere. Like a growing number of people in tech, he predicts that **in the near future, machines and artificial intelligence will do most of our work for us, and many jobs will disappear.** All those jobless people will still need money. **Selling personal data could be an important source of income,** he suggests. . . . Etwaru thinks this is a step toward a more enlightened future. **Health records are merely the test case for Hu-manity.co: Afterward comes financial data, then the geolocation data that your cell phone and car collect on you. Eventually, the whole data universe.**").

### **We fail to see how this bill promotes transparency.**

We are told patients will be more informed if this bill is passed, because they will be able to track the sale of their information through the use of block chain technology. Yet nothing in this bill provides government oversight of this new system.

We invite you to think for a moment about a bad actor in the system. Again, we don't aim to impugn the motives of the proponents of this particular bill. But as we have mentioned before, they are not the only entity that wants to jump into this new market.

Imagine you've sign up with one of these companies, and perhaps downloaded a phone application that purports to show you exactly how and when and to whom your data is being sold. And remember, this company is going to receive a cut of the proceeds, each and every time a sale happens.

Again, we are left with numerous questions:

- What assurance do we have that patients will be given all the information they need to truly make informed decisions about each of those sales?
- We've been told government is incapable of adequately watching and regulating our current system, so what would really be different here?
- Is it really true that private for-profit companies are going to be our watchdogs and protectors, and if so, who will be watching them?
- And again, once a sale has taken place and a purchaser has accessed our data sets, how do we truly know that secondary sales will not take place?

### **We also have deep concerns about unintended consequences for crucial research that aims to improve the health and well-being of Oregonians.**

The truth is there are legitimate reasons for de-identified health information to be shared. Yes, it would be worth exploring the sale of this information and whether our privacy laws need to be updated.

But we should be cautious about throwing monkey wrenches before we truly understand their impact. And here, we worry about how this bill could impact research that helps doctors improve patient care, that cures disease, and that improves health outcomes for our communities.

### **There are other ways to address these privacy concerns, none of which require a "property" model of privacy.**

Entities supporting this policy shift argue that we should trust them to create transparency in the system and protect our rights. These *new* industry players that want to profit off our health data are telling us that the problem we face is an *old* industry that is already profiting off our health data.

We believe this is a false dichotomy, and there are other options available to us.

**If we want to create greater protections for transparency and patient privacy, we can do that without redefining privacy as property.**

We have heard the suggestion that government is incapable of enhancing our medical privacy rights without this bill, and that the existing industry players are too powerful to overcome if we aim to create new privacy protections. Yet this bill is aiming to overcome those same industry players. So how, then, are we powerless to create change? We do not believe that to be the case.

**We can revisit our laws that regulate the flow of health information, look for improvements, and consider additional restrictions.**

The truth is we already have laws that do this, like HIPPA and additional privacy protections at the state level. But it is certainly worth looking at those laws more closely to see how they might be improved and adapted to the digital age. We do not doubt that our privacy laws need updating. We only doubt that this is the correct path.

**We can beef up government enforcement of our privacy rights.**

Our state DOJ regularly advocates for consumer protection, and there is no reason we could not explore potential gaps in their authority (or another agency's authority) to investigate the unlawful transfer and sale of private information, and their authority to take legal action against those who break our privacy laws.

**We can better enable consumers to understand what is happening with their data and to advocate for their own privacy rights.**

Greater transparency about what happens to our health information does not require a reframing of privacy as property. Instead, we can simply look for ways to improve the information that must be disclosed to patients and the tools exist for patients to become informed. We can also revisit the methods patients have to individually advocate for their rights, and we can update and strengthen existing legal avenues for justice.

For these reasons, the ACLU of Oregon urges you to *Vote No on SB 703*. At the same time, **we hope the sponsors of this bill know that we would be honored to participate in discussions—with all stakeholders at the table that advocate for the public interest—about potential improvements to our health privacy laws moving forward.** Please feel free to contact us if you have any questions, comments, or concerns.