

## OPPOSE SB 703

Senate Bill 703 proposes to ban the HIPAA<sup>1</sup>-compliant transfer of de-identified data without individual consent. SB 703 is a vendor-driven bill, introduced absent any consultation with Oregon's health care and research industry stakeholders. SB 703 could have significant, unintended impacts on the flow of de-identified, HIPAA-compliant health information for purposes of research, observational analyses and development of genetic-based medicine. The information subject to HB 703 is de-identified data with considerable benefits for public health, research and advancement.

**Background** SB 703 was introduced at the request of Humanity.co, a company seeking profit from sale of its technology platform, Human Data Consent and Authorization Blockchain (HD-CAB), which would benefit proponents of the bill by slowing the current flow of aggregated health data at the expense of patients and consumers. Humanity.co's own CEO has publicly stated that the company is looking to be "a title company for your digital identity."<sup>2</sup>

SB 703 is not about privacy of personal information; instead, it is about creating a demand for proprietary technology at the risk of significantly slowing the legitimate flow of de-identified vital and beneficial data.

### Examples of current uses of HIPAA-compliant, de-identified data:

- Development of diagnostics and potential cures for genetic-based diseases
- Observational research analyses, clinical trials, health trends and epidemiology studies
- Comparative effectiveness research based on competent and reliable scientific data
- Healthcare economic information for formulary decision-making
- Actuarial and health analytic information for assessing health care risks and costs
- Information sharing between health-care providers, diagnostic testing companies and other secondary health care companies for the purposes described above

### SB 703 is Significantly Flawed

- SB 703 could drive up health care costs by requiring all current HIPAA-covered entities to purchase superfluous blockchain technology (directly from the bill's proponents) and seeking consent to use de-identified patient data.
- The requirements of SB 703 seek to expand federal HIPAA law and state laws which do not require individual consent for the sharing of de-identified data. Further, the release required by SB 703 may result in a waiver of patient protection under HIPAA.
- SB 703 requires cost and complexity in obtaining patient authorization at the point of care. Providers must capture the individual authorization in the electronic health record ("EHR") before legitimately transferring the data. These costs will be borne by providers without clear understanding of how patients are remunerated. The providers would have to pay for these technical changes to EHR, likely driving up overall health care costs and slowing safe, legitimate transfer of data unnecessarily.

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<sup>1</sup> United States. (2004). *The Health Insurance Portability and Accountability Act (HIPAA)*. Washington, D.C.: U.S. Dept. of Labor, Employee Benefits Security Administration.

<sup>2</sup> "New blockchain ledger will let you sell personal healthcare data" available online at <https://www.computerworld.com/article/3301870/emerging-technology/new-blockchain-ledger-will-let-you-sell-your-personal-data.html>

- SB 703 is inconsistent with US Food & Drug Administration guidance encouraging sharing and collaboration among research entities for the advancement of individualized, genetic-based medicine.
- SB 703 lacks sufficient exceptions for exchange of de-identified data for a broad range of legitimate purposes to advance medical technology and protect the public health. SB 703 could significantly slow access to data related to critical clinical trials.
- SB 703 ignores the significant patient protections offered by HIPAA and the Genetic Information Nondiscrimination Act which balances patient rights to data, with the needs of the medical community to employ such aggregated data for applicable legal requirements and potential future medical uses; all of which may require a transfer unauthorized by SB 703.
- SB 703 creates significant challenges for diagnostics companies and other service providers that don't have direct contact with patients.
- SB 703 would require providing an individual the option to share in remuneration received from the sale of de-identified health information – an option which is neither contemplated nor tested under federal law or regulation. This requirement would be impossible to operationalize without *re-identification* of the original source of any de-identified information. SB 703 provides no parameters or protections for use of the *re-identified* data (necessary for compensation).
- SB 703 fails to restrict how data may be used after consent is granted by an individual.

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