



AMERICAN CIVIL LIBERTIES UNION

Maine

PO Box 7860
Portland, ME 04112
(207) 774-5444
www.aclumaine.org

TESTIMONY OF MEAGAN SWAY, ESQ.

Ought to Pass – LD 1902

An Act to Protect Personal Health Data

Joint Standing Committee on Judiciary

May 22, 2023

Senator Carney, Representative Moonen, and members of the Joint Standing Committee on Judiciary, good morning. My name is Meagan Sway and I am Policy Director for the American Civil Liberties Union of Maine, a statewide organization committed to advancing and preserving civil liberties guaranteed by the Maine and U.S. Constitutions through advocacy, education, and litigation. On behalf of our members, we support LD 1902.

If enacted, LD 1902 would provide needed protections over the privacy of people's health data. Among other things, it would (1) require apps and websites, search engines and advertisers, and other entities from selling, collecting, and sharing people's health data without their opt-in consent; (2) prohibit "geofences"¹ from being used around an entity that provides in-person health care services when that geofence is used to identify, track, collect data from or send notifications to a consumer that enters the geofence; (3) require entities that collect people's personal health data to maintain and publish a privacy policy for consumers' health data; and (4) create a private right of action for entities that violate the law as well as make violations of the law an unfair trade practice.

The United States does not have a comprehensive data privacy law that requires transparency and accountability for how companies can use an individual's data. As a result, people have little insight into—and even less control over—how their personal information is collected, used, shared and sold. While many think that federal Health Information Portability and Accountability Act (HIPAA) protects all their private health data, HIPAA actually only covers data collected by specific health care entities, including most health care providers. Website and app data, among others, are not protected by HIPAA.

¹ "Geofences" are virtual perimeters drawn on a map around a physical location. Apps, websites, and devices can be programmed to send advertisements or messages to individuals when they enter a specific location. This is a tactic frequently used by digital advertisers.

As a result, people's health information is left vulnerable to be shared by a variety of people, from targeted advertisers to anti-choice prosecutors. Period tracking apps, for example, can sell sensitive information about a person's late period or miscarriage to data brokers, who can link that information to a profile for sale on the open market. Law enforcement from states with strict anti-abortion laws can purchase that data profile and use that information to prosecute people who had an abortion or miscarriage in another state. Here are just a few real-world examples of how a lack of protections has played out across the country:

- In May 2022, Motherboard revealed that SafeGraph, a location data broker, sold the aggregated location data of people who visited abortion clinics for just \$160. The data showed where patients traveled from, how much time they spent at healthcare centers, and where they went afterwards. The data collected by the company includes an analysis of where people appear to live, based on where their cell phones are commonly located overnight²
- Women who experienced a pregnancy loss have been prosecuted after they searched online for medication abortion information³
- Patients waiting for emergency medical care in Philadelphia were targeted with ads for personal injury lawyers⁴

Protecting Mainers' private health information from data abuse is crucial. It is especially important in a post-*Dobbs* world. Many states have moved rapidly to criminalize abortion care and jeopardize access to needed health care services. In this new landscape, data shared between companies, private parties, and the government could be used to target and harass individuals who seek or access reproductive or gender-affirming care. This has a chilling effect on both people who need medical care, and the providers who are licensed to give it. Maine should protect access to health care and protect the medical privacy of everyone in Maine by voting ought to pass on this legislation.

² Joseph Cox, *Data Broker Is Selling Location Data of People Who Visit Abortion Clinics*, Motherboard Tech by Vice, May 3, 2022, available at <https://www.vice.com/en/article/m7vzjb/location-data-abortion-clinics-safegraph-planned-parenthood>.

³ Lauren Rankin, *How an online search for abortion pills landed this woman in jail*, Fast Company, Feb. 20, 2020, available at <https://www.fastcompany.com/90468030/how-an-online-search-for-abortion-pills-landed-this-woman-in-jail>.

⁴ Bobby Allyn, *Digital Ambulance Chasers? Law Firms Send Ads to Patients' Phones Inside ERs*, NPR, May 25, 2018, available at <https://www.npr.org/sections/health-shots/2018/05/25/613127311/digital-ambulance-chasers-law-firms-send-ads-to-patients-phones-inside-ers>.