

May 19, 2023

To: Senator Carney, Representative Moonen, and Honorable members of the Judiciary Committee

From: Hannah G. Babinski

Re: Testimony in Support of LD 1902, "An Act to Protect Personal Health Data"

Good morning, Senator Carney, Representative Moonen, and Honorable members of the Judiciary Committee, my name is Hannah G. Babinski. I am a resident of Portland, and I am writing today as a student of the University of Maine School of Law and a privacy advocate to testify in support of LD 1902, "An Act to Protect Personal Health Data." For the following reasons, I respectfully urge you to vote "Ought to Pass" on LD 1902.

Prior to beginning law school at the University of Maine School of Law, where I focus on Information Privacy Law, I was under the impression that HIPAA governed all health information. After learning what HIPAA actually covers, I was hit with the realization that much of the health information about individuals shared in the modern day is not only not protected by HIPAA but not protected by any legislation at all, federally or otherwise. This gap in coverage and protection, among other reasons, necessitates the development of legislation like LD 1902. For the following reasons, I urge you to vote "Ought to Pass" on LD 1902:

- **LD 1902 Acts as a Regulatory Gap-Filler to Existing Deficits.** LD 1902 fills the current regulatory gap left by HIPAA, protecting health data that is not "covered," including health data collected by apps on smartphones, WebMD and other medical or quasi-medical website searches, and data collected by smart devices like Apple watches and Fitbit devices. These services and devices collect extremely sensitive personal health data and, currently, lack even the most basic data privacy protections. This is not only ineffective to protect sensitive health data generally but dangerous.
- **A Lack of Effective Regulation Negates Existing HIPAA Protections.** A lack of effective regulation of such personal health data negates the protections already established by HIPAA. If personal health information is being tracked and collected by third parties via apps, services, and devices that consumers believe are private and safe and such information is similar to that of the health information maintained by doctors and other HIPAA "covered entities," then the protections established by HIPAA are null and void since the private information may still be shared absent protections at will by the third parties. As such, LD 1902 is a natural extension of the protections of HIPAA and a bolster the existing regulations.
- **There is Currently a Lack of Consumer Understanding and Consent to Data Collection and Sharing.** Most consumers are completely unaware that their sensitive health information is even being collected and likely shared at the direction of the collecting third parties when utilizing services, websites, and devices. As such, under the current system, consumers are offered no way to consent to the collection and sharing of their private information.
- **LD 1902 Acts as a Protective Measure for Women's Rights and Healthcare.**

- Following the recent and controversial reversal of the decision of *Roe v. Wade* in *Dobbs v. Jackson Women's Health Organization*, many neighboring states have enacted regressive policies, limiting if not wholly eliminating abortion access rights for women. Without comprehensive federal privacy protections and the safety net established in the *Roe v. Wade* decision to fall back on, LD 1902 acts as a protective measure for women seeking reproductive healthcare access and protects them from any retaliation or discrimination as a result of their own healthcare decision-making in the state of Maine.
  - Further, these restrictions apply to companies that collect personal information related to a person's reproductive or sexual health and gender-affirming care, including information such as data related to pregnancy, menstruation, surgery, termination of pregnancy, contraception, basal body temperature, or diagnoses. As such, LD 1902 would protect people who, for example, use fertility or period-tracking apps or are seeking information about reproductive health services.
- **LD 1902 Restricts Geo-Fencing Around Healthcare Facilities.** Since geofencing has been used to track individuals entering and exiting healthcare facilities, a restriction on such use would allow individuals to seek healthcare without fear of discrimination. For example, such a restriction would protect the privacy of individuals entering, say, Planned Parenthood, an HIV treatment clinic, an STD testing facility, a cancer treatment facility, and so on. This provision could also help women and other persons seeking reproductive care from neighboring states with restrictions on reproductive healthcare and abortion services who could travel to Maine for care.
- **A Lack of Effective Regulation Has a Chilling Effect on Speech and Expression.** A lack of effective regulation and protection from health-related information being shared may result in Mainers feeling unsafe to be honest about their health and their concerns. For example, with the knowledge that health-related websites, like WebMD, collect sensitive health information and share such information at will, individuals may be less likely to explore symptoms they may be experiencing or conduct research into specific diagnoses they have received from a healthcare professional. Likewise, since some health apps and devices track female menstruation and health conditions, individuals may feel as though they have to lie about their health in order to preserve their privacy. Privacy fears should never stand in the way of healthcare.
- **LD 1902 Provides Individuals with the Ability to Exercise Basic Privacy Rights.**
  - LD 1902 would provide Mainers with the necessary and basic privacy rights to access and delete their reproductive health information. Further, the bill would require companies to disclose what information they process and why, providing transparency and ensuring that the companies that maintain sensitive health data are held accountable. These basic privacy rights echo the rights established by law in several other states, including California, and internationally with the General Data Protection Regulation, or GDPR. Maine should, thus, follow the precedent of the other states that have taken part in instilling privacy rights for our citizens and protecting Mainers against abuse and misuse of health data.

- Likewise, LD 1902 provides Mainers with a private right of action. This provision allows Mainers to take on companies that violate their privacy and empowers them to bring suit, which not only places more control in the hand of Maine citizens but also ensures that companies take regulations seriously.
- **The Protections of LD 1902 are Not Unduly Burdensome on Companies.** LD 1902 would require businesses and non-governmental organizations to act responsibly and treat the personal information concerning reproductive health care in their stewardship with care and consideration. Specifically, this bill would restrict third parties from collecting, using, retaining, or disclosing reproductive health information that is not essential to providing the consumer requested services.

For these reasons, I respectfully urge this Committee to vote **“Ought to Pass” on LD 1902**. Thank you for your time and consideration.

Respectfully Submitted,

Hannah G. Babinski