



May 22, 2023

Chair Anne Carney
Chair Matt Moonen
Joint Standing Committee on the Judiciary
Maine Legislature
100 State House Station
Room 438
Augusta, ME 04333

Re: Maine L.D. 1902, Maine Health Privacy Legislation — *SUPPORT*

Dear Chair Carney and Chair Moonen,

Consumer Reports sincerely thanks you for your work to advance consumer privacy in Maine. L.D. 1902 would extend to Maine consumers important new protections relating to their personal health data, including prohibitions against collecting or sharing consumer health data without affirmative opt-in consent, a ban on data sales, the right to know the personal health data companies have collected about them and well as the right to delete that information.

Many companies that collect especially sensitive personal information, including personal health data, are failing to safeguard it. For example, a 2021 Consumer Reports investigation into seven of the leading mental health apps showed that they had significant privacy issues: many shared user and device information with social media companies and all had confusing privacy policies that few consumers would understand.¹ Similarly, the Federal Trade Commission has recently enforced against several companies that improperly shared personal health information with

¹ Thomas Germain, Mental Health Apps Aren't All As Private As You May Think, Consumer Reports, (March 2, 2021), <https://www.consumerreports.org/health-privacy/mental-health-apps-and-user-privacy-a7415198244/>

third-parties or broke their privacy promises to consumers, including fertility tracker apps Flo² and Premom³, online counseling service BetterHelp⁴, and online prescription company GoodRx.⁵

Even when companies do not outright lie about their privacy protections, the hazy bounds of existing privacy law further complicate consumers' ability to understand company data practices. In a 2023 study headed by University of Pennsylvania researchers, 82% of consumers didn't realize that HIPAA does not apply to many health-related data in mobile apps.⁶ As a result, many consumers share sensitive health information with businesses under the illusion that it has preexisting legal protections, when, in many cases, none exist.

Lawmakers need to remedy this imbalance. At a minimum, businesses should be required to transparently communicate to consumers when they are collecting and sharing health data, and this data should *only* be disclosed if consumers give an affirmative opt-in consent. While Consumer Reports would prefer a framework that prevents the collection *and* secondary use of personal health data for any purposes other than providing the service requested by the consumer, we are glad to see that L.D. 1902 includes strong protections that would improve consumer privacy.

In particular, we appreciate that L.D. 1902 includes:

- *A strong definition of consumer health data.* The definition of consumer health data included in this legislation covers key categories of personal information consumers may share with businesses that deserve additional protection, including among others, health conditions and interventions, biometric or genetic data, use or purchase of medication, and gender-affirming care.

² Federal Trade Commission, FTC Finalizes Order with Flo Health, a Fertility-Tracking App that Shared Sensitive Health Data with Facebook, Google, and Others, (June 22, 2021), <https://www.ftc.gov/news-events/news/press-releases/2021/06/ftc-finalizes-order-flo-health-fertility-tracking-app-shared-sensitive-health-data-facebook-google>

³ Federal Trade Commission, Ovulation Tracking App Premom Will be Barred from Sharing Health Data for Advertising Under Proposed FTC Order, (May 17, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/05/ovulation-tracking-app-premom-will-be-barred-sharing-health-data-advertising-under-proposed-ftc>

⁴ Federal Trade Commission, FTC to Ban BetterHelp from Revealing Consumers' Data, Including Sensitive Mental Health Information, to Facebook and Others for Targeted Advertising, (March 2, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/03/ftc-ban-betterhelp-revealing-consumers-data-including-sensitive-mental-health-information-facebook>

⁵ Federal Trade Commission, FTC Enforcement Action to Bar GoodRx from Sharing Consumers' Sensitive Health Info for Advertising, (February 1, 2023), <https://www.ftc.gov/news-events/news/press-releases/2023/02/ftc-enforcement-action-bar-goodrx-sharing-consumers-sensitive-health-info-advertising>

⁶ Turow, J., Lelkes, Y., Draper, N. A., & Waldman, A. E, Americans Can't Consent To Companies' Use Of Their Data, (February 20, 2023), https://repository.upenn.edu/asc_papers/830/

- *Restrictions on collecting and sharing without consent and prohibition on sales.* L.D. 1902 requires that regulated entities obtain separate, specific consents to respectively collect and share consumer health data. It also bans the sale of consumer health data outright. Importantly, the bill requires that any consent to *share* consumer health data must be obtained separately from consent to *collect* consumer health data, which itself cannot be bundled into a general terms of service. However, we note that the distinction between sharing and selling is often blurry, and may be confusing to consumers. Instead of bifurcating sharing and sales into separate frameworks, we suggest prohibiting all data disclosures to third-parties unless reasonably necessary to provide the service.
- *Strong enforcement.* Given the AG’s limited resources, a private right of action is key to incentivizing companies to comply and we appreciate that one is included in the bill. We strongly encourage legislators to retain this provision going forward. Under an AG-only enforcement framework, businesses that recognize that the AG is only capable of bringing a handful of enforcement actions each year might simply ignore the law and take their chances in evading detection. Further, it’s appropriate that consumers are able to hold companies accountable in some way for violating their rights.
- *Prohibitions on geofencing.* Individuals should be able to receive in-person health care services without fearing that companies are tracking their visits and/or disclosing that information to additional third-parties. Potential uses or disclosure of such information could result in consequences that range from embarrassing to outright adversarial. For example, businesses could share healthcare visit information with insurance companies who could then use it as a basis to increase monthly premiums. Some third-parties may even disclose or be forced to disclose geofenced data with law enforcement. L.D. 1902 appropriately bans such activity.

We note one loophole that should be closed in order to provide Maine consumers with the protections they deserve:

- *Clarify that the non-discrimination provision means price or service discrimination.* While we appreciate that the bill prohibits regulated entities from discriminating against consumers that exercise their rights under this act, the term “discriminate” is not defined or otherwise explained, which could lead regulated entities from construing the term narrowly. For that reason, we urge the drafters to specifically include prohibitions against price and service discrimination. Additionally, the legislation should ensure that the non-discrimination provisions apply to *all* consumer rights under the bill, including those in Section 1350-R. We suggest the following language:

(a) A business shall not discriminate against a consumer because the consumer

exercised any of the consumer's rights under Section 1350-Q or Section 1350-R, or did not agree to information processing for a separate product or service, including, but not limited to, by:

- (1) Denying goods or services to the consumer.*
- (2) Charging different prices or rates for goods or services, including through the use of discounts or other benefits or imposing penalties.*
- (3) Providing a different level or quality of goods or services to the consumer.*
- (4) Suggesting that the consumer will receive a different price or rate for goods or services or a different level or quality of goods or services.*

We look forward to working with you to ensure that Maine consumers have the strongest possible privacy protections.

Sincerely,

Matt Schwartz
Policy Analyst