



July 19, 2024

Chairman Phil Mendelson
Council of the District of Columbia
1350 Pennsylvania Avenue, NW, Suite 504
Washington, D.C. 20004

Re: Consumer Health Information Privacy Protection Act of 2024 — *SUPPORT*

Dear Chairman Mendelson,

Consumer Reports sincerely thanks you for your work to advance consumer privacy in D.C. The Consumer Health Information Privacy Protection Act (CHIPPA) would extend to D.C. consumers important new protections relating to consumer health data, including prohibitions against collecting such data without consent, sharing that data without separate and distinct consent, and selling that data without written or electronic authorization, as well as the right to know the consumer health data companies have collected about them and the right to delete that information.

Many companies that collect especially sensitive personal information, including consumer health data, are failing to safeguard it. For example, Consumer Reports recently found that several health-related sites continued to share data with third parties, even after receiving opt-out requests.¹ Similarly, 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.²

Additionally, the Federal Trade Commission has recently enforced against several companies that improperly shared personal health information with third-parties or broke their privacy

¹ Oates et al., Companies Continue to Share Health Data Despite New Privacy Laws, Consumer Reports (January 16, 2024), <https://advocacy.consumerreports.org/wp-content/uploads/2024/01/Companies-Continue-to-Share-Health-Data-1-16-2024-Consumer-Reports.pdf>

² 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/>

promises to consumers, including fertility tracker apps Flo³ and Premom⁴, online counseling service BetterHelp⁵, and online prescription company GoodRx.⁶

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 did not realize that HIPAA's privacy protections do not apply to many health-related data in mobile apps.⁷ As a result, many consumers share sensitive health information with businesses under the illusion that it is protected by preexisting legal frameworks, 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 personal health information. And while Consumer Reports would prefer a framework that, by default, prevents the collection *and* secondary use of consumer health information for *any* purposes other than providing the service requested by the consumer, we are glad to see that CHIPPA includes strong protections that would improve consumer privacy.

In particular, we appreciate that CHIPPA includes:

- *A strong definition of consumer health data.* The definition of “consumer health data” includes any information linked or reasonably linkable to a consumer that identifies their past, present, or future physical “physical or mental health status,” which covers key categories of personal information consumers may share with businesses that deserve heightened protection. We also appreciate that inferences companies make that relate to consumers' physical or mental health data are covered.

³ 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>

⁴ 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>

⁵ 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>

⁶ 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>

⁷ 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/

- *A private right of action.* Given the AG’s limited resources, a private right of action is key to incentivizing companies to comply and we appreciate that one is provided for via reference to D.C.’s existing unfair and deceptive trade practices statute. 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. We strongly encourage the Council to retain this provision going forward.
- *Restrictions on collection without consent, opt-in for sharing, and written authorization for sales.* CHIPPA requires that regulated entities obtain consent to collect consumer health data. Importantly, the bill also requires businesses to receive separate, specific opt-in consent to share consumer health data and further separate authorization to sell consumer health data — though we’d prefer to see sales of consumer health data banned outright. Nevertheless, the proposed structure will at least ensure that consent for such unanticipated secondary uses of information cannot be bundled into a general terms of service or blanket privacy policy and instead must be presented to consumers in a standalone format.
- *Non-discrimination provisions.* We appreciate that the bill prohibits regulated entities from discriminating against consumers that exercise their rights under this act. However, we suggest that drafters specify that “unlawful discrimination” includes the charging of different prices or rates for products or services or by providing a different level of service or quality when consumers exercise their rights, as has been done in numerous analogous state privacy laws.⁸

For these reasons, we strongly urge passage of CHIPPA. We look forward to working with you to ensure that D.C. consumers have the strongest possible privacy protections.

Sincerely,

Matt Schwartz
Policy Analyst

⁸ See, e.g., Maryland Online Data Privacy Act of 2024, Section 14–4607(a)(6), <https://mgaleg.maryland.gov/2024RS/bills/sb/sb0541E.pdf>

