



January 30, 2024

Chair Steven Otis
Science & Technology Committee
New York State Assembly
LOB 739
Albany, NY 12248

Re: New York A.B. 4983/S. 158, New York Health Privacy Legislation — *SUPPORT*

Dear Chair Otis,

Consumer Reports sincerely thanks you for your work to advance consumer privacy in New York. A.B. 4983/S. 158 would extend to New York consumers important new protections relating to their personal health data, including prohibitions against processing consumer health data for secondary purposes without affirmative consent, a ban on data sales and sharing, the right to know the personal health data companies have collected about them and 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, 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 Maggie 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. While Consumer Reports would prefer a framework that, by default, prevents the collection *and* secondary use of personal health information for any purposes other than providing the service requested by the consumer, we are glad to see that A.B. 4983/S. 158 includes strong protections that would improve consumer privacy.

In particular, we appreciate that A.B. 4983/S. 158 includes:

- *A strong definition of regulated health information.* The definition of “regulated health information” included in this legislation covers key categories of personal information consumers may share with businesses that deserve additional protection, including any inferences that companies make that relate to consumers physical or mental health.
- *Restrictions on processing without consent and a prohibition on sales.* A.B. 4983/S. 158 requires that regulated entities obtain separate, specific consent to process regulated health information unless such processing is strictly necessary to provide a product or

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/

service requested by the individual. It also bans the sale of regulated health information outright. Importantly, the bill's definition of sale means *sharing* regulated health information for monetary or other valuable consideration, which closes a common loophole in opt-out privacy laws that prevents consumers from requesting that businesses cease *all* commercial disclosure of their personal information. Additionally, the bill ensures that consent for processing regulated health information cannot be bundled into a general terms of service and must be presented to consumers in a standalone format.

- *Meaningful non-discrimination provisions.* We appreciate that the bill prohibits regulated entities from discriminating against consumers that exercise their rights under this act, including by charging different prices or rates for products or services or by providing a different level of service or quality. Importantly, the bill also provides that consumers can reject processing of regulated health information not strictly necessary to provide the service and still use the service.

For these reasons, we strongly urge passage of A.B. 4983/S. 158. We look forward to working with you to ensure that New York consumers have the strongest possible privacy protections.

Sincerely,

Matt Schwartz
Policy Analyst

cc: Speaker Carl Heastie
Majority Leader Andrea Stewart-Cousins
Members, Assembly Science and Technology Committee
Assembly Member Rosenthal