FUTURE OF PRIVACY FORUM

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October 28, 2024

Chair Christina Henderson
D.C. Council Committee on Health
1350 Pennsylvania Avenue, NW
Washington, DC 20004

Dear Chair Henderson and Members of the Committee,

As the D.C. Council considers the important issue of safeguarding health data, the Future of Privacy Forum ("FPF") writes with feedback on the role of consent in the Consumer Health Information Privacy Protection Act of 2024 ("CHIPPA").[1] FPF is a non-profit organization dedicated to advancing privacy leadership, scholarship, and principled data practices in support of emerging technologies in the United States and globally.[2]

We commend the DC Council's efforts to advance individual health data privacy rights and protections. CHIPPA is closely modeled on Washington State's My Health, My Data Act enacted in 2023,[3] though we note a divergence that may result in significantly different experiences for covered individuals between the frameworks. Under the My Health, My Data Act, a business may typically collect and use health data under two circumstances: (1) if necessary to provide a product or service requested by an individual, or (2) with the affirmative consent of the individual.[4] However, CHIPPA provides that collection and use of health data is *only* permissible when a business first obtains an individual's consent, even when the collection is necessary to provide the service.[5] Under CHIPPA, without a basis for collecting and using health data if "necessary" to provide a requested product or service, individuals would need to receive notice and provide affirmative choice in every instance where their health data would be collected, used, or transferred in order to use a product or service that relies on health information.

Providing a notice and explanation of data collection and an opportunity to consent can be a beneficial tool for helping empower individuals to control the use of their personal information - particularly in the context of inherently sensitive categories of information such as health data. However, overreliance on consent requirements may also add complications to user experiences with little or no benefit to the individual. A legal framework that requires consent for all data processing may lead to individuals being overexposed to pop-ups, banners, or other consent

[1] B25-0930, the Consumer Health Information Privacy Protection Act of 2024.
[2] The opinions expressed herein do not necessarily reflect the views of FPF's supporters or Advisory Board.
[3] RCW 19.373, My Health, My Data Act (2023) Sec. 5(1).
[4] *Id*. § Sec.(1).
[5] B25-0930 § 4.

requests and mechanisms, to the point where individuals cease to meaningfully engage with their privacy choices.[6] This potential drawback is particularly salient when noting the prescriptive and detailed disclosures required for valid consent under CHIPPA and the expansive definition of "consumer health data" which could encompass a broad array of records such as grocery, clothing, and personal hygiene purchases.[7]

Significant scholarship has been dedicated to "consent fatigue" – the name of the stage when an individual is less likely to take full advantage of reading, understanding, and exercising their rights if there is an overload of information and options.[8] The issue of "consent fatigue" is further exacerbated if the same consent mechanisms are required for data collection and processing with vastly different use cases or risks.

Under CHIPPA, a business must not only obtain consent for unnecessary second uses (such as the use of the same location data to advertise local fitness stores), but also for data without which the service cannot function as intended and anticipated (such as the use of location data in an app that track's a user's jogging history). Requiring the same consent for both necessary and unnecessary data processing activities may lead to individuals being less engaged with consent requests that do provide a meaningful opportunity to accept or decline data collection and transfers. Furthermore, in instances where collecting health data is necessary for the product or service that an individual is requesting, requirements to obtain separate consent may be redundant for individuals. For example, an individual who has purchased a health app for the purpose of tracking their meals is unlikely to expect or benefit from a requirement to provide additional specific consent for the app to collect records about the food that the individual affirmatively uploads to the app.

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[6] *See e.g.* Woodrow Hartzog, *Testimony before the Senate Commerce Committee* (February 27, 2019), https://www.commerce.senate.gov/services/files/8B9ADFCC-89E6-4DF3-9471-5FD287051B53.
[7] *See* B25-0930 Sec. 2(9) and 4(a) and David Stauss and Keir Lamont, *The year that was in state data privacy*, IAPP (Oct. 20, 2023), https://iapp.org/news/a/the-year-that-was-in-state-data-privacy.
[8] *See* Milovan Jovicic, *UX blindspot: Cookie diabetes and consent fatigue*, (Dec. 19, 2020) https://uxdesign.cc/ux-blindspot-cookie-diabetes-and-consent-fatigue-d53220292a0a; Christine Utz, Martin Degeling, Sascha Fahl, Florian Schaub, Thorsten Holz, *(Un)informed Consent: Studying GDPR Consent Notices in the Field*, (Oct. 19, 2019), https://arxiv.org/abs/1909.02638; Vicki Ha, Kori Marie, Farah Al Shaar, Lina Hdeib, *An examination of user perception and misconception of internet cookies*, (Apr. 21, 2006), https://dl.acm.org/doi/10.1145/1125451.1125615; Daniel J. Solove, *The Myth of the Privacy Paradox*, (Jan. 29, 2021), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3536265.

In considering this important legislation, FPF recommends the Council ensure that CHIPPA empowers individuals with the ability to make meaningful choices regarding the use of their health data, focusing on unexpected or high risk uses or their information.

Thank you for the opportunity to provide input. If you have any questions, please contact Bailey Sanchez at bsanchez@fpf.org.

Sincerely,

Bailey Sanchez
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Future of Privacy Forum