

5-17-2023

**FOOL ME ONCE ... WHY THE AMERICAN DATA PRIVACY ACT  
PROPOSAL FAILS TO ADEQUATELY DETER DATA PRIVACY  
VIOLATIONS**

Melissa Mann

Follow this and additional works at: <https://scholarship.law.slu.edu/lawjournalonline>



Part of the [Constitutional Law Commons](#), and the [Health Law and Policy Commons](#)

---

## FOOL ME ONCE ... WHY THE AMERICAN DATA PRIVACY ACT PROPOSAL FAILS TO ADEQUATELY DETER DATA PRIVACY VIOLATIONS

MELISSA MANN\*

While health data privacy is not an entirely new concern, the recent United States Supreme Court decision in *Dobbs v. Jackson Women's Health Organization* brought this issue back to the forefront of public concern, reinforcing apprehension around the data privacy law framework in the US and health app use.<sup>1</sup> There are more than 318,000 health apps available, with sixty-five percent of smartphone users downloading at least one of those apps and using it daily.<sup>2</sup> Many people now utilize health tracking apps for various medical and wellness-related reasons while the information collected can be viewed or collected by other entities, used by vendors to send specific ads, or sold to data brokers that obtain and share consumer information without their knowledge, typically selling it for marketing or other purposes.<sup>3</sup> Legal experts note that data like search history, text messages, and location data could be used in court and, in some cases, already have been.<sup>4</sup> Having health information shared without your knowledge can have serious repercussions that could affect your ability to obtain life insurance and how much you pay for that coverage, increase the

---

\*J.D. Candidate, May 2024, St. Louis University School of Law

<sup>1</sup> Emilie Smith, *Cycle-Tracking Apps and Data Privacy in the Post-Roe Climate*, MARQ. UNIV. LAW SCH. FAC. BLOG (Oct. 11, 2022), <https://law.marquette.edu/facultyblog/2022/10/cycle-tracking-apps-and-data-privacy-in-the-post-roe-climate/>. *Dobbs* has left many attorneys waiting to see how the decision will affect traditional privacy law frameworks, since considering *Roe v. Wade* was based on finding a place for abortion within the privacy protections of the Constitution.

<sup>2</sup> Raymond J. March, *Medical Apps: Improving Healthcare on a Global Scale*, CATALYST (Sep. 24, 2018), <https://catalyst.independent.org/2018/09/24/medical-apps-improving-healthcare-on-a-global-scale/>.

<sup>3</sup> *When Does HIPAA Apply to Health Apps?*, FOCAL POINT INSIGHTS (Oct. 03, 2018), <https://blog.focal-point.com/when-does-hipaa-apply-to-health-apps.>; *Protecting the Privacy and Security of Your Health Information When Using Your Personal Cell Phone or Tablet*, U.S. DEP'T OF HEALTH AND HUM. SERV., <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/cell-phone-hipaa/index.html>. Mobile apps can collect a variety of information provided by the app user, including information typed or uploaded into the app (medical records, medical history, photos, etc.) as well as information provided by the user's device like location.

<sup>4</sup> FOCAL POINT INSIGHTS, *supra* note 3.

interest rate you are charged on loans, leave you vulnerable to workplace discrimination, and possibly be used against you in trial to name a few.<sup>5</sup>

Health apps owned by tech companies are not subject to HIPAA regulations, leaving voluntarily given and de-identified health data unprotected.<sup>6</sup> Additionally, the Federal Trade Commission's (FTC) Health Breach Notification Rule (HBNR) does not cover voluntarily given information, still making users of health apps vulnerable to potential data misuse without recourse.<sup>7</sup> To bridge the gap between HIPAA and FTC privacy frameworks, the Biden-Harris Administration proposed the American Data Privacy Protection Act (ADPPA) to provide consumers various rights to access, correct, export covered data, opt out of data transfers, and delete data that identifies or is linked or reasonably linkable to an individual.<sup>8</sup> The Act applies broadly to the United States to cover entities that fall under FTC jurisdiction and generally allows those entities to collect and make use of user data if it's necessary for one of the permitted purposes but does stipulate that reasonable measures in ensuring data cannot at any point be used to re-identify an individual need to be taken.<sup>9</sup>

---

<sup>5</sup> *Id.*

<sup>6</sup> Nicolas P. Terry, Regulatory Disruption and Arbitrage in Health-Care Data Protection, 17 *YALE J. HEALTH POL'Y L. & ETHICS* 143, 181 (2017).

<sup>7</sup> 16 C.F.R. § 318.; HEALTH LAW LIVE, Episode 42: *Data Privacy in a Post Dobbs World: Professor Sinha*, (SLU Law, Sep. 15, 2022), <https://www.slu.edu/law/podcast/post-dobbs-data-privacy-ep42.php> (timestamp at 11:09). For most social media, consumers sign on to a privacy policy when registering, which most people are unlikely to read or understand.

<sup>8</sup> *Overview of the American Data Privacy and Protection Act, H.R. 8152*, CRS (Aug. 31, 2022), <https://crsreports.congress.gov/product/pdf/LSB/LSB10776>.; *Marking the 50th Anniversary of Roe: Biden-Harris Administration Efforts to Protect Reproductive Health Care*, U.S. DEP'T OF HEALTH AND HUM. SERV., <https://www.hhs.gov/sites/default/files/roe-report.pdf>.; H.R.8152, 117th Congress (2021-2022).; Qiuyang Zhao, *American Data Privacy and Protection Act: Latest, Closest, yet Still Fragile Attempt Toward Comprehensive Federal Privacy Legislation*, Harvard (Oct. 19, 2022), <https://jolt.law.harvard.edu/digest/american-data-privacy-and-protection-act-latest-closest-yet-still-fragile-attempt-toward-comprehensive-federal-privacy-legislation#:~:text=For%20covered%20entities%2C%20the%20ADPPA,protection%2C%20and%20privacy%20by%20design>.

<sup>9</sup> CRS, *supra* note 8.; Gilad Edelman, *Don't Look Now, but Congress Might Pass an Actually Good Privacy Bill*, WIRED (Jul. 21, 2022), <https://www.wired.com/story/american-data-privacy-protection-act-adppa/>.; H.R.8152, 117th Congress (2021-2022).

Enforced by the FTC, ADPPA allows individuals a private right of action.<sup>10</sup> However, a plaintiff's relief is limited to seeking recovery of an amount equal to the sum of any compensatory damages, injunctive relief, declaratory relief, and reasonable attorney's fees and litigation costs.<sup>11</sup> Further, lawsuits are restricted to federal courts, and covered entities are provided with mechanisms to mitigate the risk of such claims through the use of arbitration provisions and class action waivers.<sup>12</sup>

The need for a federal data privacy law is clear and has bipartisan support.<sup>13</sup> Once enacted, there may be little impetus to pass further legislation, underscoring the importance of enacting a federal data privacy law that adequately addresses issues restricting individual autonomy over personal health data. Recently, Flo Health Inc.'s Flo Period & Ovulation Tracker, which boasts 25 million active users, was found to have been sharing information about users' menstrual cycles and pregnancy plans with Facebook without disclosing its data-sharing intentions to users even after claiming to have kept sensitive information confidential from third-party vendors.<sup>14</sup> The FTC settled this matter with Flo through various orders to restore its data privacy compliance.<sup>15</sup> Yet, Flo's arbitration clause does not

---

<sup>10</sup> David Stauss & Shelby Dolen, *Analyzing the American Data Privacy and Protection Act's Private Right of Action*, BYTE BACK (Aug. 01, 2022), <https://www.bytebacklaw.com/2022/08/analyzing-the-american-data-privacy-and-protection-acts-private-right-of-action/>.

<sup>11</sup> *Id.*

<sup>12</sup> *Id.*; H.R.8152, 117th Congress (2021-2022). ADPPA section 403(e) lists limitations of lawsuits that can be brought while section 403(e)(2) lists exclusions for certain small businesses.; Cara Hartley, American Data Privacy and Protection Act (ADPPA), TERMSFEED, <https://www.termsfeed.com/blog/adppa/#:~:text=The%20FTC%20can%20penalize%20businesses,up%20to%20%2446%2C517%20per%20violation>. The FTC can penalize businesses that don't comply with the ADPPA with fines of up to \$46,517 per violation.

<sup>13</sup> Beth L. Goldstein et al., *Drive for Federal Privacy Legislation Continues in 2023*, THE NATIONAL LAW REVIEW (Feb. 14, 2023), <https://www.natlawreview.com/article/drive-federal-privacy-legislation-continues-2023>. The move toward a privacy legislation looks promising in the 118<sup>th</sup> Congress, despite the significant change in landscape.

<sup>14</sup> Sam Schechner, *You Give Apps Sensitive Personal Information. Then They Tell Facebook.*, THE WALL STREET JOURNAL (Feb. 22, 2019), <https://www.wsj.com/articles/you-give-apps-sensitive-personal-information-then-they-tell-facebook-11550851636>.

<sup>15</sup> Lesley Fair, *Health App Broke Its Privacy Promises By Disclosing Intimate Details About Users*, F.T.C. (Jan. 13, 2021), <https://www.ftc.gov/business-guidance/blog/2021/01/health-app-broke-its-privacy-promises-disclosing-intimate-details-about-users>.

allow a plaintiff to seek monetary recovery, and this limitation could likely still exist even if the ADPPA was passed.<sup>16</sup> And, if Flo was a company without a physical presence in the U.S., it would not be implicated by the ADPPA for data collected on a U.S. citizen as it only applies to U.S. entities.<sup>17</sup> ADPPA expands the scope of U.S. covered entities applying to entities beyond what HIPAA and FTC's HBNR would cover; however, it also does not turn on the sensitivity of the data that is being misused.

If a federal data privacy law needs to be structured by the type of entities it covers, then it needs sincerely hold those entities accountable for violations. To deter companies from undermining individuals' privacy rights more effectively, it is essential to broaden the scope of a federal data privacy regulation to include entities outside of the U.S. that target American citizens, increase penalties for violators, and empower individuals with an expanded private right of action. These measures would likely help incentivize companies to comply with privacy regulations more than the current "return to compliant" orders and potential damages faced that are proposed by the ADPPA. Beyond "reasonable measures" to secure data, there should be an express provision prohibiting covered entities from attempting to re-identify de-identified information enforced with rigorous civil and criminal penalties for violators.<sup>18</sup>

---

<sup>16</sup> F.T.C., Decision and Order, In the Matter of FLO HEALTH, INC., a corporation., Docket No. C-4747.; Hartley, *supra* note 12. The FTC can penalize businesses that don't comply with the ADPPA with fines of up to \$46,517 per violation.; *What is GDPR, the EU's new data protection law?*, GDPR, <https://gdpr.eu/what-is-gdpr/> (last visited Mar. 10, 2023). Violations of the EU GDPR can result in significant financial fines up to ~\$21,188,000.00.

<sup>17</sup> Daniel K. Alvarez, *T Minus One Year (and Counting): The EU General Data Protection Regulation Is Set to Take Effect in May 2018 – Are You Ready?*, BLOOMBERG LAW (May 25, 2017), [https://www.bloomberglaw.com/product/blaw/document/XJ6FEA9C/download?search32=IFaw1TmJiLXFr1M7GO6uGg==DqGsITkh4tNct\\_bGmJRfdRxaFZCoc3pyitEX3UwckWanGJN\\_K9F\\_1VGz8zyKBUCSoe\\_E0GczFVo4eX9Xkl236L3xXIhXRySoIWGt7-lpgDnX0m5yq47kGR9TbX5CPDvM](https://www.bloomberglaw.com/product/blaw/document/XJ6FEA9C/download?search32=IFaw1TmJiLXFr1M7GO6uGg==DqGsITkh4tNct_bGmJRfdRxaFZCoc3pyitEX3UwckWanGJN_K9F_1VGz8zyKBUCSoe_E0GczFVo4eX9Xkl236L3xXIhXRySoIWGt7-lpgDnX0m5yq47kGR9TbX5CPDvM). The GDPR applies to any processing of personal data of EU citizens, regardless of where the data is collected or processed. Non-EU companies can also be subject to GDPR if they collect data from EU citizens.

<sup>18</sup> Sharona Hoffman, Citizen Science The Law and Ethics of Public Access to Medical Big Data, 30 BERKELEY TECH. L. J. 1741, 1792 (2015).

With public concerns over data privacy reaching a fever pitch in the post-*Dobbs* landscape, Congressional efforts to meaningfully address the issue still fall short. Lawmakers need to recognize the urgency of enacting a comprehensive federal privacy law that addresses individual autonomy concerns rather than reacting to public pressures, attempting to pass a privacy law that appeases the public but lacks comprehensiveness.