

**2023 – 2024 Legislative Memorandum**

**Subject: New York Health Information Privacy Act  
A.4983-A (L. Rosenthal) / S.158-A (Krueger)**

**Position: SUPPORT**

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From Fitbits to smartwatches to period tracking apps, New Yorkers increasingly use apps, devices, and other digital tools, to monitor and maintain our physical and mental health. And, in the digital age, companies use sophisticated algorithms to ascertain our health information, aggregate data about us, and turn our electronic health data in to profit. For example, as long ago as 2012, Target was using shoppers’ purchasing habits to identify when they were pregnant – often before they themselves knew.<sup>1</sup>

But, in the wake of the Supreme Court’s decision to overturn *Roe v. Wade*, the stakes are even higher. It is impossible to have an abortion without leaving a digital trail. There will be search histories; possibly phone records, travel itineraries, or Fitbit or period-tracker app data; changes in purchasing history that suggest a pregnancy; and the list goes on. In fact, electronic health data have already been used to prosecute people for supporting others to access abortion care.<sup>2</sup>

We need stronger privacy protections.

A.4983-A (L. Rosenthal) / S.158-A (Krueger) builds on the provisions enacted in Part U of the FY2024 Health and Mental Hygiene (HMH) Article VII legislation<sup>3</sup> to holistically protect New Yorkers’ electronic health data as well as electronic health data generated in New York. The NYCLU urges its immediate passage.

HMH Part U took important first steps toward protecting New Yorkers’ electronic health data. It limited when electronic service providers headquartered or incorporated in New York can respond to out-of-state warrants for reproductive health information; prohibited New York law

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<sup>1</sup> Charles Duhigg, *How Companies Learn Your Secrets*, NY TIMES, Feb. 16, 2012, <https://www.nytimes.com/2012/02/19/magazine/shopping-habits.html>.

<sup>2</sup> E.g. Josh Funk, *Nebraska woman charged with helping teenage daughter have abortion*, AP, Aug. 9, 2022, [https://www.pbs.org/newshour/health/nebraska-woman-charged-with-helping-daughter-have-abortion#:~:text=OMAHA%20\(AP\)%20%E2%80%94%20Nebraska,to%20burn%20the%20fetus%20afterward](https://www.pbs.org/newshour/health/nebraska-woman-charged-with-helping-daughter-have-abortion#:~:text=OMAHA%20(AP)%20%E2%80%94%20Nebraska,to%20burn%20the%20fetus%20afterward).

<sup>3</sup> A.3007-C/S.4007-C Part U, 2023-2024 Reg. Sess. (N.Y. 2023).

enforcement from buying any electronic health data; and required New York law enforcement to get a warrant if they want to obtain electronic health data.

But these protections are not enough. New York cannot bind out-of-state law enforcement, nor can New York prevent a hostile state's law enforcement from obtaining New York electronic health data simply by serving legal process at a company's offices in that hostile state without ever setting foot in New York or going before a New York court.

A.4983-A/S.158-A patches these critical gaps. This measure gives New Yorkers control over our electronic health data and makes it harder for law enforcement in a hostile state to use those data to prosecute New Yorkers for providing, receiving, or helping another to access to health care – whether that is abortion care, gender-affirming care, or any other type of health care.<sup>4</sup>

The bill prohibits the sale of New Yorkers' electronic health data and electronic health data generated in New York, including to out-of-state buyers, and requires affirmative consent for all processing of New Yorkers' electronic health information and electronic health data generated in New York unless that processing is strictly necessary for a short list of enumerated purposes. It includes a default expectation that electronic health data will be deleted after sixty days unless the individual to whom it pertains requests that it be retained longer, and it provides individuals with access and deletion rights. The bill also includes data security provisions and effective enforcement mechanisms and prohibits companies from charging people more or treating them differently because they exercise their privacy rights under the legislation.

If A.4983-A/S.158-A passes, companies will be required to collect less electronic health data from New Yorkers and in New York, they will delete the data they do have regularly, and New Yorkers will have more control over our electronic health data. This is critical: a hostile state's law enforcement cannot access electronic health data a company does not have – even if they are able to bypass New York's courts.

Moreover, even for those who do not fear criminalization, electronic health data are personal, and we should be in the position to decide how, when, and why our health data are processed and with whom they are shared.

Because we believe that New Yorkers deserve control over our electronic health data, and because we believe that no one should worry that their health data will be used to criminalize them, the NYCLU strongly supports A.4983-A/S.158-A and urges its immediate passage.

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<sup>4</sup> In the wake of the *Dobbs* decision, nearly half the states are poised to completely ban abortion – and many already have. See generally *Interactive Map: US Abortion Policies and Access After Roe*, GUTTMACHER INSTITUTE, May 22, 2023, <https://states.guttmacher.org/policies/>; *After Roe Fell: Abortion Laws by State*, CENTER FOR REPRODUCTIVE RIGHTS, <https://reproductiverights.org/maps/abortion-laws-by-state/> (last visited May 24, 2023). Similarly, seventeen bills to ban gender affirming care have become law in states across the country. See generally *Mapping Attacks on LGBTQ Rights in U.S. State Legislatures*, ACLU, May 19, 2023, <https://www.aclu.org/legislative-attacks-on-lgbtq-rights>.