

**MEMORANDUM OF SUPPORT OF THE NEW YORK HEALTH INFORMATION
PRIVACY ACT**

A.4983A (L. Rosenthal) / S.158A (Krueger)
May 26, 2023

The Surveillance Technology Oversight Project supports the New York Health Information Privacy Act A.4983A (L. Rosenthal) / S.158A (Krueger) and urges the legislature to pass, and the Governor to sign, this bill.

In 2023, it is impossible to have an abortion without leaving a digital trail. There will be search histories; possibly phone records, travel itineraries, Fitbit or period-tracker app data; changes in purchasing history that suggest a pregnancy; and more. In fact, as long ago as 2012, Target was using shoppers' purchasing habits to identify when they were pregnant – often before they themselves knew.¹ More recently, electronic health data have been used to prosecute people for supporting others to access abortion care.²

We need stronger privacy protections.

The Surveillance Technology Oversight Project litigates and advocates for privacy, working to abolish local governments' systems of mass surveillance. Our work highlights the discriminatory impact of surveillance on Muslim Americans, immigrants, the LGBTQ+ community, indigenous peoples, and communities of color, particularly the unique trauma of anti-Black policing. With the fall of *Roe v. Wade*, the need to ensure the privacy of New Yorkers' data, especially from government surveillance, is more important than ever.

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 legislation³ to protect New Yorkers' electronic health data as well as electronic health data generated in New York.

The New York Health Information Privacy Act gives New Yorkers control over electronic health data and makes it harder for law enforcement in a hostile state to use those data to

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

² *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).

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

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.⁴

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.

New Yorkers deserve control over our electronic health data. No one should worry that their health data will be used to criminalize them. For these reasons, the Surveillance Technology Oversight Project urges the legislature to pass and the Governor to sign A.4983A (L. Rosenthal) / S.158A (Krueger).

⁴ 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>.