

March 5, 2025

The Honorable Kathy Hochul
Governor of New York State
NYS Capitol Building
Albany, NY 12224

Dear Governor Hochul,

We are civil rights organizations; reproductive health, rights, and justice groups; LGBTQ+ advocacy organizations; privacy advocates; and consumer protection groups. Some of us are health care providers who offer abortion care; some provide gender-affirming care. Some provide both. We write to urge you to immediately sign S.929/A.2141, the New York Health Information Privacy Act.

We have always known that electronic health data are personal, and we have always believed that individuals should be in the position to decide how, when, and why our health data are processed and with whom they are shared.

But, in the current moment, the stakes for health data privacy are infinitely higher. Since the U.S. Supreme Court overturned *Roe v. Wade*, more than half of states have severely restricted access to abortion¹ – and thirteen states have completely banned abortion.² Similarly, thirty-seven bills to ban gender affirming care have become law in states across the country.³ Meanwhile, the Trump administration has already begun to coerce hospitals into denying gender-affirming care,⁴ and its backers have made clear that overturning *Roe v. Wade* was just the beginning – their ultimate aim is to eliminate access to abortion across the country.

It is impossible to have an abortion or seek gender-affirming care – or to support someone to receive such care – without leaving a digital trail. There will be search histories; email exchanges; possibly phone records, travel itineraries, or Fitbit or period-tracker app data; in the case of abortion, changes in purchasing that suggest a pregnancy;⁵ and the list goes on. In fact, electronic health data have already been used to prosecute people for supporting others to access abortion care.⁶

¹ *Interactive Map: US Abortion Policies and Access After Roe*, GUTTMACHER INSTITUTE, Jan. 29, 2025, <https://www.guttmacher.org/state-legislation-tracker>.

² *After Roe Fell: Abortion Laws by State*, CENTER FOR REPRODUCTIVE RIGHTS, <https://reproductiverights.org/maps/abortion-laws-by-state/> (last visited Feb. 4, 2025).

³ *See generally* Mapping Attacks on LGBTQ Rights in U.S. State Legislatures, ACLU, Feb. 7, 2025, <https://www.aclu.org/legislative-attacks-on-lgbtq-rights>.

⁴ Exc. Order No. 14187, 90 Fed. Reg. 8771 – 73 (Feb. 3, 2025).

⁵ For example, as long ago as 2012, Target was using shoppers' purchasing habits to identify when they were pregnant – often before they themselves knew. *See* Charles Duhigg, *How Companies Learn Your Secrets*, NY TIMES, Feb. 16, 2012, <https://www.nytimes.com/2012/02/19/magazine/shopping-habits.html>.

⁶ *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).

We need stronger privacy protections.

S.929/A.2141 complements the provisions enacted in Part U of the FY2024 Health and Mental Hygiene (HMH) Article VII legislation⁷ to holistically protect New Yorkers' electronic health data as well as electronic health data generated in New York. We urge its immediate passage.

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 data 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. This is critical: 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. But, a hostile state's law enforcement cannot access electronic health data a company does not have – even if they are able to bypass our courts.

The bill also includes data security provisions and prohibits companies from charging people more or treating them differently because they exercise their privacy rights under the legislation.

We know that New Yorkers increasingly use apps, devices, and digital tools, like Fitbits, smartwatches, and period tracking apps, to monitor and maintain our physical and mental health, and we believe that we should have control over our electronic health data when we use these modern tools. Moreover, New Yorkers should be able to use these tools without worrying that the health data they collect could be used to criminalize us. For these reasons, we strongly support S.929/A.2141 and urge you to immediately sign it.

Sincerely,

Aria Medical Clinic
BKForge: Brooklyn for Reproductive and Gender Equity
Callen-Lorde Community Health Center
Center for Digital Democracy
Consumer Reports
Housing Works, Inc.
If/When/How: Lawyering for Reproductive Justice
National Abortion Federation
National Council of Jewish Women NY
National Institute for Reproductive Health
National Women's Law Center
New York Civil Liberties Union
New York State Coalition Against Domestic Violence

⁷ A.3007-C/S.4007-C Part U, 2023-2024 Reg. Sess. (N.Y. 2023).

New York Reproductive Health Access Cluster
NYCD16/15-Indivisible
Oakland Privacy
Planned Parenthood Empire State Acts
Privacy Rights Clearinghouse
Public Health Solutions
Reproductive Health Access Project
Surveillance Technology Oversight Project
Virginia Citizens Consumer Council
WCLA - Choice Matters