

June 5, 2023

Majority Leader Andrea Stewart-Cousins
New York State Senate
330 Capitol Building
Albany, NY 12247

Speaker Carl Heastie
New York State Assembly
932 Legislative Office Building
Albany, NY 12248

Dear Leader Stewart-Cousins and Speaker Heastie,

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 in strong support of A.4983-A (L. Rosenthal) / S.158-A (Krueger), 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* almost a year ago, nearly half the states are poised to completely ban abortion – and many already have.¹ Similarly, eighteen bills to ban gender affirming care have become law in states across the country.²

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;³ and the list goes on. In fact, electronic health data have already been used to prosecute people for supporting others to access abortion care.⁴

We need stronger privacy protections.

¹ 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).

² 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>.

³ 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>.

⁴ 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).

A.4983-A/S.158-A complements the provisions enacted in Part U of the FY2024 Health and Mental Hygiene (HMH) Article VII legislation⁵ 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 effective enforcement mechanisms 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 A.4983-A/S.158-A and urge its immediate passage.

Sincerely,

Aria Medical
The Center for HIV Law and Policy
Electronic Frontier Foundation
Family Planning of South Central New York, Inc.
Housing Works
MYA Network
National Institute for Reproductive Health Action Fund
National Women’s Law Center
New York Civil Liberties Union
NYCD16 Indivisible
NYS American Academy of Pediatrics, Chapters 1, 2 & 3
Planned Parenthood Empire State Acts

⁵ A.3007-C/S.4007-C Part U, 2023-2024 Reg. Sess. (N.Y. 2023).

Public Health Solutions
Reproductive Health Access Project
Reproductive Health Access Project, New York Chapter
Surveillance Technology Oversight Project
WCLA – Choice Matters

CC. Members of the Senate and Assembly