

2023 – 2024 Legislative Memorandum

Subject: Requiring all health information systems or electronic health record systems to segregate certain patient information from the rest of such patient’s medical record S.7879-A (Fernandez) / A.8884-A (Lunsford)

Position: SUPPORT

Electronic health records improve the quality of health care by ensuring that every provider who sees a patient has access to their medical history.¹ But, electronic health records also make a patient’s entire medical record – including records about sensitive health care – available to all providers with access to the system. And, by default, the information in a patient’s electronic health record can be shared across state lines automatically. As other states criminalize abortion care and gender affirming care, this automatic sharing can put New York patients who travel or move to ban states, as well as the New York providers who care for them, at risk of criminalization. It further poses risks of discrimination against New York patients by other providers in New York who oppose abortion, gender affirming care, or other sensitive types of health care they previously received.

S.7879-A (Fernandez) / A.8884-A (Lunsford) would require the Department of Health to promulgate regulations compelling the electronic health record companies to create the ability to segment electronic health records and suppress sensitive health information at a patient’s direction. This would enable patients to reap the benefits of electronic health records without risking that information about their abortion, gender affirming care, or other sensitive health care will be shared against their will and used against them. The NYCLU strongly supports this legislation and urges its immediate passage.

Similar measures are already law in Maryland² and California,³ and the major electronic health record companies are already taking steps to comply⁴ in those states, which should streamline implementation in New York.

¹ See *Electronic Health Records*, CENTERS FOR MEDICARE & MEDICAID SERVICES, Sept. 6, 2023, <https://www.cms.gov/priorities/key-initiatives/e-health/records>.

² H.B. 812/S.B. 785, 2023 Leg. (Md. 2023) (signed into law May 3, 2023).

³ A.B. 352, 2023 Leg. (Cal. 2023) (signed into law Sept. 27, 2023).

⁴ E.g. *Chapter 249 (House Bill 812), Health – Reproductive Health Services – Protected Information and Insurance Requirements Implementation Update*, MARYLAND HEALTH CARE COMMISSION, Apr. 18, 2024,

Since the Supreme Court’s decision in *Dobbs v. Jackson Women’s Health Organization*, which ended the constitutional right to abortion, more than half of the states have restricted access to abortion care.⁵ And, in the past two years, at least thirty-two bills have passed in states across the country targeting medically necessary health care for transgender, gender non-conforming, and nonbinary (TGNCNB)⁶ people.⁷ Electronic health records create unique vulnerabilities for patients and providers when treatment that is health care in New York is criminalized in other states. For example, an abortion provider in an access state tells the story of a patient who traveled for care and then sought follow-up care in her home state of Texas. The access state provider reported, “I sat down at my computer and saw her note from the [Texas doctor] . . . And I thought, ‘Oh God, if I can see *their* note, then they must be able to see *my* note,’” which included prescriptions and instructions for medication abortion.⁸ Another provider learned that one of her patients was reported to Child Protective Services in her home state after a health care provider there learned through her medical record that she had traveled for abortion care. Indeed, a report from a health care provider is the most common way that people come to the attention of law enforcement for allegedly ending their own pregnancies or helping someone else to do.⁹

But, interstate concerns are not the only issues animating S.7879-A/A.8884-A. The NYCLU has heard from people who worry about discrimination from the health care providers or insurers here in New York based on an abortion noted in their electronic health records. Because they know their medical records are not private and may be used against them, some people do not provide complete information to their medical providers. For example, fearing discrimination or criminalization, people have refused to share the date of their last menstrual period with their doctors.¹⁰

The regulations S.7879-A/A.8884-A contemplates would require the electronic health record companies to create the ability to segment, at the patient’s direction, abortion and gender-affirming care information, as well as records pertaining to STI and HIV testing and treatment, mental health services, alcohol or substance abuse treatment, and records of any

https://mhcc.maryland.gov/mhcc/pages/home/meeting_schedule/documents/presentations/2024/20240418/agd6_comm_implementation.pdf.

⁵ See *Interactive Map: US Abortion Policies and Access After Roe*, GUTTMACHER INSTITUTE, <https://states.guttmacher.org/policies/> (last updated May 1, 2024).

⁶ Because these bills typically include exemptions for identical treatments when forced onto intersex youth, this memo refers only to TGNCNB people without adding an “I” for intersex.

⁷ See generally *Mapping Attacks on LGBTQ Rights in U.S. State Legislatures*, ACLU, <https://www.aclu.org/legislative-attacks-on-lgbtq-rights?impact=health> (last updated May 17, 2024) (compiling legislation).

⁸ Christine Henneberg, *The Trade-Offs for Privacy in a Post-Dobbs Era*, WIRED, June 5, 2023, <https://www.wired.com/story/the-trade-offs-for-privacy-in-a-post-dobbs-era/>.

⁹ Laura Huss, Farah Diaz-Tello, & Goleen Samari, *Self-Care Criminalized: August 2022 Preliminary Findings*, IF/WHEN/HOW: LAWYERING FOR REPRODUCTIVE JUSTICE, 2022, https://ifwhenhow.org/wp-content/uploads/2023/06/22_08_SMA-Criminalization-Research-Preliminary-Release-Findings-Brief_FINAL.pdf.

¹⁰ EmeraldGirl, *Declined to give my LMP at the doctor’s office*, REDDIT, https://www.reddit.com/r/TwoXChromosomes/comments/w5aall/declined_to_give_my_lmp_at_the_doctors_office/ (last visited Apr. 11, 2024).

other health care services determined by the Commissioner of Health in consultation with health care providers and patient advocates. This capability would enable patients to benefit from electronic health records without risking that their health information will be used against them.

New Yorkers should be able to reap the benefits of electronic health records without worrying that the information in their health records could be used to criminalize or discriminate against them. For these reasons, the NYCLU strongly supports S.7879-A/A.8884-A and urges its immediate passage.