



June 16, 2023

VIA ELECTRONIC TRANSMISSION

U.S. Department of Health and Human Services, Office for Civil Rights,
Attention: HIPAA and Reproductive Health Care Privacy NPRM,
Hubert H. Humphrey Building, Room 509F, 200 Independence Avenue SW,
Washington, DC 20201

**Re: RIN 0945-AA20
HIPAA Privacy Rule to Support Reproductive Health Care Privacy**

I. Introduction

The Center for Democracy & Technology (CDT) respectfully submits these comments in response to a notice of proposed rulemaking (NPRM) from the Department of Health and Human Services (HHS, the Department) proposing modifications to the Standards for Privacy of Individually Identifiable Health Information (Privacy Rule), issued pursuant to the Health Insurance Portability and Accountability Act of 1996 (HIPAA).¹ CDT is a nonprofit 501(c)(3) organization dedicated to advancing privacy, consumer, and civil rights for all in the digital age, and has focused on the importance of health privacy generally² and reproductive health privacy in particular.³

CDT agrees that, as a result of the Supreme Court's decision in *Dobbs v. Jackson Women's Health Organization*⁴ and the subsequent enactment of laws in multiple states criminalizing abortion, patients are at greater risk of having their sensitive health information disclosed in connection with abortion-related investigations and prosecutions. That, in turn, is undermining trust in health care providers and making individuals less likely to seek health care in the first place, or share important information about their health history and symptoms if they do. CDT

¹ HIPAA Privacy Rule To Support Reproductive Health Care Privacy, 88 Fed. Reg. 23506 (Apr. 17, 2023), perma.cc/JR29-BVB7.

² Andrew Crawford & Michelle Richardson, *CDT & eHI's Proposed Consumer Privacy Framework for Health Data*, Ctr. for Democracy & Tech. (Feb. 9, 2021, 2:00 PM), perma.cc/8WEC-ZETR (discussing *Proposed Consumer Privacy Framework for Health Data*, Ctr. for Democracy & Tech. (Feb. 2021), perma.cc/BK75-WPAP); Andrew Crawford, *Placing Equity at the Center of Health Care & Technology*, Ctr. for Democracy & Tech. (Mar. 2022), perma.cc/A6LE-TD7F; *Healgorithms: Understanding the Potential for Bias in mHealth Apps*, Ctr. for Democracy & Tech. (Sept. 13, 2018), perma.cc/WP34-TC97.

³ Andrew Crawford, *Data After Dobbs: Best Practices for Protecting Reproductive Health Data*, Ctr. for Democracy & Tech. (May 2023), perma.cc/RP4A-MNXZ [hereinafter Crawford, *Data After Dobbs*]; *Protecting Reproductive Rights & Access to Information*, Ctr. for Democracy & Tech., perma.cc/YW8V-WQZQ (May 31, 2023, 2:09 PM).

⁴ *Dobbs v. Jackson Women's Health Org.*, 597 U.S. ____ (2022).



supports the proposed rule because it would help prevent these harmful effects and thereby protect patients, and offers some ways in which the rule should be strengthened.

II. HIPAA and its associated Privacy Rule fail to adequately protect patient health records in the wake of the *Dobbs* decision.

Although HIPAA and its associated Privacy Rule have contained an exception allowing disclosure of Protected Health Information (PHI) to law enforcement in certain circumstances, the *Dobbs* decision and subsequent state-level criminalization of abortions and associated health care have transformed what was a narrow exception to one that systematically puts reproductive health care information at risk.⁵

Prior to the Supreme Court's overturning of *Roe v. Wade*,⁶ patients had little reason to believe their data would be subject to law enforcement requests for abortion-related investigations, because abortions were generally legal in the United States. Once the protections of *Roe* and its progeny were removed, states immediately began restricting and criminalizing abortion.⁷ As of June 2023, sixteen states have laws that permit the prosecution of people who provide, or otherwise aid in the procurement of, abortions with few to no exceptions.⁸ Some of these laws permit prosecution even in cases of abuse and incest.⁹ Four states explicitly criminalize self-managed abortions,¹⁰ although, between 2000 and 2020, twenty-six states investigated or

⁵ HIPAA's Privacy Rule establishes broad provisions regarding disclosures to law enforcement, health oversight & public health officials. 45 C.F.R. § 164.512(f).

⁶ *Roe v. Wade*, 410 U.S. 113 (1973)

⁷ *Id.*; see *After Roe Fell: Abortion Laws By State*, Ctr. for Reproductive Rts., perma.cc/P5CM-MXF4 (June 13, 2023, 11:52 AM).

⁸ See, e.g., Idaho Code § 18-605, perma.cc/3FGQ-CMV5; Idaho Code § 18-606, perma.cc/6Z8R-PSUU; La. Stat. Ann. § 14:87.7, perma.cc/L9WY-MPZZ (2023); La. Stat. Ann. §40:1061(D), perma.cc/7JX9-SE9M; La. Stat. Ann. § 40:1061.29, perma.cc/5EFP-9HXW; S.D. Codified Laws § 22-17-5.1 (2023), perma.cc/SR4Q-D6VF; Tex. Health & Safety Code § 170A.004, perma.cc/DH2Y-YSYN (2023); Wyo. Stat. Ann. § 35-6-125 (2023), perma.cc/2KJ2-BHZZ.

⁹ See, e.g., Tex. Health & Safety Code § 170A.002, perma.cc/L3ZQ-F3PC; Daniel Breen, *Lawmakers reject child rape, incest exceptions to Arkansas abortion ban*, KUAR (Mar. 30, 2023, 1:50 PM), perma.cc/6ZE4-GG4D (reporting on H.B. 1670, 94th Gen. Assemb., Reg. Sess. (Ark. 2023), perma.cc/PF2E-GVXM).

¹⁰ South Carolina, Idaho, Oklahoma, and Nevada. S.C. Code Ann. § 44-41-80(b) (2023), perma.cc/RQ74-M8CA; Idaho Code § 18-606(2); Okla. Stat. tit. 63, § 1-733 (2023), perma.cc/F9ZN-C9JH; Nev. Rev. Stat. Ann. § 200.220 (LexisNexis 2023), perma.cc/7HEA-X3FZ; see Lyn Riddle & Poppy Noor, *South Carolina woman arrested for allegedly using pills to end pregnancy*, Guardian (Mar. 3, 2023, 3:32 PM), perma.cc/YNX8-XRM2.

arrested people for self-managed abortions.¹¹ A few states also allow for private citizens to bring civil actions against abortion providers.¹²

With these new laws in place after *Dobbs*, state-level law enforcement agencies have new incentives to seek and use patient PHI in criminal prosecutions for people seeking, providing, or assisting with reproductive health care, including abortions.¹³ That reality has led to a loss of trust between patients and providers.¹⁴ When health data is not kept private, patients are less willing to share their medical history, information about their symptoms, and other intimate details about themselves.¹⁵ Needless to say, patients must be able to trust their providers, and vice versa, in order to receive and administer necessary care that is up to ethical and practical standards.¹⁶ Without trust, patients will not be truthful with their doctors, or may not seek health care services at all, for fear of giving away information that leads to a prison sentence.¹⁷ This chilling effect could lead to repeated reproduction-related public health crises as providers are unable to properly care for their patients, or as potential patients are choosing not to see health professionals in the first place.¹⁸

This loss of trust will have the greatest impact on marginalized communities—including people with disabilities and people of color—whose trust in health care, especially reproductive care,¹⁹

¹¹ Laura Huss, Farah Diaz-Tello & Goleen Samari, *Self-Care, Criminalized: August 2022 Preliminary Findings, If/When/How* (Aug. 2022), perma.cc/U6UA-T5MP.

¹² Idaho Code § 18-613, perma.cc/2U5N-QVV7; Idaho Code § 618, perma.cc/9R5M-HCRP; Tex. Health & Safety Code § 171.208, perma.cc/A2G7-Z3S9; see Alan Feuer, *The Texas Abortion Law Creates a Kind of Bounty Hunter. Here's How It Works.*, N.Y. Times (Sept. 10, 2021), perma.cc/HS52-YH2N.

¹³ Eric Boodman, Tara Bannow, Bob Herman, & Casey Ross, *HIPAA won't protect you if prosecutors want your reproductive health records*, Stat (June 24, 2022), perma.cc/2Z7V-D6G8.

¹⁴ Eric Boodman, *In a doctor's suspicion after a miscarriage, a glimpse of expanding medical mistrust*, Stat (June 29, 2022), perma.cc/229B-M6VW.

¹⁵ Bradley E. Iott, Celeste Campos-Castillo & Denise L. Anthony, *Trust and Privacy: How Patient Trust in Providers is Related to Privacy Behaviors and Attitudes*, 2019 Am. Med. Informatics Assoc. Ann. Symp. Proc. 487, 490–91 (2019).

¹⁶ See Johanna Birkhäuer, Jens Gaab, Joe Kossowsky, Sebastian Hasler, Peter Krummenacher, Christoph Werner, Heike Gerger, *Trust in the health care professional and health outcome: A meta-analysis*, 12 PLOS One 1 (2017); see also Tara Montgomery, Jeffrey S. Berns & Clarence H. Braddock III, *Transparency as a Trust-Building Practice in Physician Relationships With Patients*, 324 JAMA2365 (2020).

¹⁷ See Boodman, *supra* note 14.

¹⁸ See Audrey Kearney, Grace Sparks, Ashley Kirzinger, Marley Presiado & Mollyann Brodie, *KFF Health Tracking Poll May 2023: Health Care in the 2024 Election and in the Courts*, KFF (May 26, 2023), perma.cc/3LUD-VDK4 (“Two-thirds of adults are concerned bans on abortion would make it difficult for doctors to safely treat patients, leading to complications.”).

¹⁹ See Elisa A. Mitchell, *Black Women's Reproductive Health and Legacies of Distrust*, Black Perspectives (Aug. 3, 2022), perma.cc/HM4V-MYRL; Robyn M. Powell, *Disability Reproductive Justice*, 170 U. Pa. L. Rev. 1851 (2022); Natasha Lennard, *The Long, Disgraceful History of American Attacks on Brown and Black Women's Reproductive Systems*, Intercept (Sept. 17, 2020, 9:11 AM), perma.cc/369J-EU5Y.

has already been undermined by both historical and current prejudices²⁰ and a lack of resources, among other things.²¹ The *Dobbs* decision, and the possibility that reproductive health care information could be weaponized against patients, their providers, and those who help them, exacerbates this distrust and the already unjust and dangerous gaps in the provision of health care to marginalized communities.²²

The risks of disclosure of reproductive health care information to law enforcement are not hypothetical. Even prior to *Dobbs*, state-level criminal investigators charged individuals with pregnancy-related offenses, and sought and utilized PHI as evidence in pregnancy-related prosecutions for years.²³ In 2010, a woman was arrested for attempted feticide after she fell down the stairs, went to the hospital to check on her fetus, and confessed to a nurse that she had been considering adoption or abortion—the nurse reported her statements to a doctor who called the police.²⁴ In 2019, the Missouri State Health Director testified at a hearing that he tracked Planned Parenthood patients' menstrual cycles with a spreadsheet that was compiled by the State's main inspector to help identify patients who had undergone failed abortions after the state became concerned they were not receiving complication reports for all failed surgical abortions.²⁵ The Director later denied tracking menstrual cycles, but admitted that officials had

²⁰ See Ziggy Waller, *Beyond Bias: How Hidden Racism in Medical Devices Legitimizes Oppression*, Health Just. Commons (Aug. 15, 2022), perma.cc/BPL3-Y5HM; Colin M.E. Halverson, Heather L. Penwell & Clair A. Francomano, *Clinician-associated traumatization from difficult medical encounters*, 3 SSM—Qualitative Rsch. Health 1 (2023); Ryan Thoreson, "You Don't Want Second Best": Anti-LGBT Discrimination in U.S. Health Care (2018); Ian James Kidd, Lucienne Spencer & Havi Carel, *Epistemic injustice in psychiatric research and practice*, Phil. Psych 1 (2022); Natalie M. Chin, *Centering Disability Justice*, 71 Syracuse L. Rev. 683 (2021).

²¹ See Kat Stafford, Annie Ma & Aaron Morrison, *From Birth to Death*, Associated Press (May 23, 2023), perma.cc/LUN7-BJAK; Samuel R. Bagenstos, *The New Eugenics*, 71 Syracuse L. Rev. 752 (2021); Axenya Kachen & Jennifer R. Pharr, *Health Care Access and Utilization by Transgender Populations*, 5 Transgender Health 141 (2020); Abigail Mulcahy, Carl G. Streed, Jr., Anna Marie Wallisch, Katie Batza, Noelle Kurth, Jean P. Hall & Darcy Jones McMaughan, *Gender Identity, Disability, and Unmet Healthcare Needs among Disabled People Living in the Community in the United States*, 19 Int'l J. Env't Rsch. & Pub. Health 2588 (2022).

²² See Crawford, *Data After Dobbs*, *supra* note 3; Robin S. Maril, *From Liberation To (Re)Criminalization: Dobbs v. Jackson Women's Health Organization, Bodily Autonomy, and the Expansion of State Rights*, SMU L. Rev. (forthcoming), perma.cc/S3QZ-TG76; Elizabeth Yuko, *Women of Color Will Face More Criminalized Pregnancies in Post-'Roe' America*, Rolling Stone (July 7, 2022), perma.cc/92U8-JRKH.

²³ See Cynthia Conti-Cook, *Surveilling the Digital Abortion Diary*, 50 U. Baltimore L. Rev. art. 2 (2020); Sandhya Dirks, *Criminalization of pregnancy has already been happening to the poor and women of color*, NPR (Aug. 3, 2022, 10:30 AM), perma.cc/RF92-8RUN.

²⁴ Dirks, *supra* note 23; Amie Newman, *Pregnant? Don't Fall Down the Stairs*, Rewire News Group (Feb. 15, 2010, 4:07 PM), perma.cc/4QKZ-CBA8.

²⁵ Darran Simon, *Missouri says health director didn't track Planned Parenthood patients' periods. But officials did have a spreadsheet*, CNN (Oct. 31, 2019, 2:17 AM), perma.cc/MSY9-4UYY.

the data and a spreadsheet did exist.²⁶ In 2021, a woman gave birth to a healthy baby, but provided her obstetrician a list of prescriptions she took during pregnancy, triggering an investigation and, months later, an armed raid of her house.²⁷ She was charged with felony possession involving prescription fraud because she failed to inform her prescribing doctor that she was pregnant before refilling her lawful hydrocodone prescription—the charges were not dropped until 2022.²⁸

Increasingly, law enforcement and civil litigants may turn to health care providers and companies to seek and gain access to data that could help prove that a person sought, received, aided, or provided an abortion.²⁹

A number of states that seek to protect those seeking abortions have sought to prevent the disclosure of reproductive health care information by enacting shield laws that limit the amount of information state officials and law enforcement can share with out-of-state prosecutors.³⁰ The new rule proposed by the Department provides the opportunity to extend similar protections to all peoples' PHI in certain circumstances.

²⁶ *Id.*; Yasmeen Abutaleb & Emily Wax-Thibodeaux, *Missouri reviewed data about Planned Parenthood's patients, including their periods, to identify failed abortions*, Wash. Post (Oct. 30, 2019, 6:15 PM), perma.cc/5K7F-T2XC.

²⁷ Moira Donegan, *Alabama is prosecuting a mom for taking prescribed medication while pregnant*, Guardian (July 27, 2021, 6:17 PM), perma.cc/YA8M-FPA3.

²⁸ *Id.*; *Felony Charge Dropped Against Alabama Mother Who Renewed Valid Prescription to Manage Chronic Pain During Pregnancy*, Pregnancy Justice (Feb. 23, 2022), perma.cc/4277-U8NZ.

²⁹ Crawford, *Data After Dobbs*, *supra* note 3; Christine Henneberg, *The Trade-Offs for Privacy in a Post-Dobbs Era*, Wired (June 5, 2023, 8:00 AM), perma.cc/V5LA-HAZX. See, e.g., Lauren Rankin, *How an online search for abortion pills landed this woman in jail*, Fast. Co. (Feb. 26, 2020, 7:00 AM), perma.cc/3DLV-4924.

³⁰ Fourteen states and the District of Columbia have enacted laws, and the governors of five states have issued executive orders. See, e.g., Cal. Health & Safety Code § 123466(b) (Deering 2023), perma.cc/UG92-6GF6; Cal. Health & Safety Code § 123467.5, perma.cc/Q74Y-R3BJ; Cal. Penal Code §§ 13775–79 (Deering 2023), perma.cc/KS3U-RM6R; Cal. Gov't Code §§ 6218–6218.05 (Deering 2023), perma.cc/YWW5-UN54; 2022 Conn. Pub. Acts No. 22-19 (2023), perma.cc/72YP-8LAW; 2023 Conn. Pub. Acts No. 23-56 (2023), perma.cc/GD2E-DLP7; Reproductive & Gender-Affirming Health Care Freedom Act, ch. 11, 2023 N.M. Laws (2023) (to be codified at N.M. Stat. Ann. §§ 24-34-1 to -5), perma.cc/Y9VJ-U7HQ; Reproductive and Gender-Affirming Health Care Protection Act, ch. 167, 2023 N.M. Laws (2023) (to be codified at N.M. Stat. Ann. §§ 24-10F-1 to -8, 68-1-38, and as amended at § 31-4-6), perma.cc/5H4G-QTSF; Shield Law, ch. 193, 2023 Wash. Sess. Laws (2023), perma.cc/M2J6-TQ5D; Human Rights Sanctuary Amendment Act of 2022, D.C. CODE § 2-1461.01 to 61.02 (2022), perma.cc/L828-SJS9; R.I. Exec. Order, No. 22-28 (July 5, 2022), perma.cc/K3UH-U6VW.

III. OCR should issue the proposed rule after modifying it in several ways to strengthen it.

The proposed rule is essential to helping patients maintain trust and protect the privacy of their health care choices. Patients expect their health data to stay between them and their health care provider.³¹ As set forth above, in the wake of the *Dobbs* decision, that expectation will continue to be undermined without changes like those proposed in the NPRM. The increased risk of disclosure of sensitive reproductive health care information will deter patients, particularly those from marginalized communities, from being forthcoming with their health care providers or seeking reproductive health care in the first place.³² The proposed changes would help restore at least some trust in the reproductive healthcare system, leading to fewer harms and more comprehensive health care services.

The proposed rule appropriately seeks to provide targeted protections for the privacy of reproductive health care information, but should be strengthened in several respects.

Definitions

The department should modify several proposed definitions.

The definition of “reproductive health care” should be broader. The NPRM proposes to define “reproductive health care” as “care, services, or supplies related to the reproductive health of the individual.”³³ This definition may not encompass all relevant forms of care. For instance, “related to the reproductive health of the individual” might not include activities like blood pressure measurement, vitamin use, or collection of heart rate data, which could be indicative of pregnancy or changes in reproductive health and still be obtained and used by law enforcement. To better capture the universe of data that could reveal a person’s reproductive health, the Department should expand the definition to read “care, services, or supplies related to **or that could be used to determine, predict, or estimate the past, present, or future** reproductive health of the individual.”³⁴

³¹ Rebecca B. Reingold, Lawrence O. Gostin & Michele Bratcher Goodwin, *Legal Risks and Ethical Dilemmas for Clinicians in the Aftermath of Dobbs*, 328 JAMA 1695, 1696 (2022); *Patient survey shows unresolved tension over health data privacy*, Am. Med. Assoc. (July 25, 2022, 9:00 AM), perma.cc/Q7Q4-S7DJ; see Kelly N. Michelson, James G. Adams & Joshua M. M. Faber, *Navigating Clinical and Business Ethics While Sharing Patient Data*, 327 JAMA 1025, 1025 (2022).

³² See *Patient survey shows unresolved tension over health data privacy*, *supra* note 31 (“Nearly 75% of patients expressed concern about protecting the privacy of personal health data. . . . This concern is magnified with the [*Dobbs* ruling] as the lack of data privacy could place patients and physicians in legal peril.”); Michelson, Adams & Faber, *supra* note 31 (discussing limitations of current data protections under HIPAA, including concerns about secondary data use).

³³ HIPAA Privacy Rule To Support Reproductive Health Care Privacy, 88 Fed. Reg. at 23527.

³⁴ This is similar to the approach that CDT took in our Health Privacy framework. Crawford & Richardson, *supra* note 2.

The Department should also provide more illustrative examples to accompany this definition to better ensure that any resulting rule will capture data about reproductive health care. Specifically, the definition could include examples of gender-affirming care when providing examples of “reproductive health care.” While it is possible that gender-affirming care is covered by the proposed definition already, specifically falling under “other types of care, services, or supplies used for the diagnosis and treatment of conditions related to the reproductive system,”³⁵ providing examples will ensure its coverage is clear.

As with anti-abortion laws, laws that criminalize gender-affirming care ultimately criminalize medical providers,³⁶ lead to inadequate³⁷ to completely inaccessible³⁸ health care, reinforce inequality,³⁹ and deprive people of human rights.⁴⁰ They also lead to patients not being truthful with their providers, or refusing to seek medical attention when necessary.

³⁵ HIPAA Privacy Rule To Support Reproductive Health Care Privacy, 88 Fed. Reg. at 23527.

³⁶ ch. 68, sec. 1, 2023 Colo. Sess. Laws at 240 (finding providers “fear attacks on their licensure, denial of liability insurance, and interstate prosecution,” “individuals seeking abortion care, and those who help them, face criminal prosecution,” and “the parents of youth seeking gender-affirming health care face charges of child abuse and neglect.”).

³⁷ *Id.* (anticipating further restrictions making it harder for people to access, obtain accurate information about, and travel for related services, including medications); No. 15, sec. 10a, 2023 Vt. Acts (finding “a state’s prohibition of or limitation on the provision of gender-affirming health care services or reproductive health care services, or both . . . prohibits health care providers from following health care best practices and is a failure on the part of the state to provide health care services that are medically necessary and clinically appropriate for its residents”).

³⁸ *See, e.g.*, ch. 68, sec. 1, 2023 Colo. Sess. Laws at 240–41, perma.cc/8UE8-VMLH (reporting that post-*Dobbs*, patients seeking abortion care at Colorado clinics rose 33% and Colorado residents faced wait times of up to three weeks and it’s expected that the same will happen with gender-affirming care); *Gov. Pritzker Signs Sweeping Reproductive Rights Protections Into Law*, Illinois.Gov (Jan. 13, 2023), perma.cc/8KGU-5DLP (reporting that the Attorney General called Illinois a “health care oasis for anyone seeking care”).

³⁹ *See, e.g., id.* at 241 (“As Colorado is further impacted by neighboring states’ reproductive and gender-affirming health-care restrictions, Colorado will see the same deepening of existing inequities for poor or geographically underserved people, and Black and Indigenous communities and other communities of color.”). *Compare* art. 30 Ill. Pub. Act. 102-1117 (2023) (codified at 215 Ill. Comp. Stat. Ann. 5/356z.60), perma.cc/ST6B-NNTM (requiring that insurance fully cover abortifacients, hormonal therapy medication, and HIV PrEP/PEP drugs approved by the FDA and follow-up services including mental health counseling), *with* Texas laws prohibiting or limiting coverage of abortions and PrEP/PEP. 1 Tex. Admin Code § 354.1167 (2023), perma.cc/6ETJ-D4ZJ; Tex. Ins. Code § 1218.004 (2023), perma.cc/W8DE-3HUE; *Braidwood Mgmt. v. Becerra*, No. 4:20-cv-00283-O, 2023 U.S. Dist. LEXIS 54769 (D. Tex. Mar. 30, 2023).

⁴⁰ After the Illinois shield law was signed, Mony Ruiz-Velasco, Deputy Director of Equality Illinois stated, “Reproductive rights are LGBTQ+ rights. Our rights are inextricably linked by substantive due process claims to rights to privacy, bodily autonomy, and the liberty to form one’s own family.” *Gov. Pritzker Signs Sweeping Reproductive Rights Protections Into Law*, *supra* note 38.

Protecting gender-affirming care as or in conjunction with reproductive health care has precedent.⁴¹ Colorado’s shield law provides a similar definition of “reproductive health care,” identifying “gender-affirming health-care services” among its corresponding list of examples and specifying care “at all stages of life” is included.⁴² Other shield laws join reproductive and gender-affirming health care together under broader definitions of “lawful,”⁴³ “protected,”⁴⁴ and “legally-protected”⁴⁵ health care.⁴⁶ Additionally, a 2023 Congressional Research Service report defines “human reproductive health services” as “preventive, diagnostic, and treatment services related to reproductive systems, functions, and processes”⁴⁷ and names “gender-affirming services” as one of the “six types of reproductive health services.”⁴⁸

Reproductive and gender-affirming health care are linked because many reproductive health centers also offer gender-affirming care, including hormone replacement therapy.⁴⁹ Individual providers of abortion and other pregnancy-related care may also provide gender-affirming

⁴¹ Eight states—California, Colorado, Connecticut, Illinois, Massachusetts, New Mexico, Washington, and Vermont—and the District of Columbia, include gender-affirming care in their shield laws. Online Privacy for Reproductive Health Services Providers, Employees, Volunteers, and Patients Act, ch.

191, sec. 1, 3 Cal. Stat. 4231, 4234 (2021), perma.cc/6R8L-KCT2; Protections for Accessing Reproductive Health Care Act, ch. 68, 2023 Colo. Sess. Laws 239, 240–46; Conn. Pub. Acts No. 23-56; Patient & Provider Protection Act, arts. 6, 7, 28, 30, Ill. Pub. Act. 102-1117; Mass. Ann. Laws ch. 12, § 111½ (LexisNexis 2023), perma.cc/QG7H-Y84X; Mass. Ann. Laws ch. 147, § 63, perma.cc/G9Z4-BKAW; ch. 11, 2023 N.M. Laws; ch. 167, 2023 N.M. Laws; ch. 193, 2023 Wash. Sess. Laws; Civil and Criminal Procedures Involving Legally Protected Health Care Activity Act, No. 14, 2023 Vt. Acts (2023), perma.cc/LP3K-TRWV; Legally Protected Health Care Activity and Provider Regulation Act, No. 15, 2023 Vt. Acts (2023), perma.cc/F72A-SXYN; D.C. Code § 2-1461.01. *Cf.* L.B. 574, 108th Leg. (Neb. 2023) (enacted), perma.cc/2Q56-VKY8 (demonstrating there is also precedent for banning gender-affirming care and reproductive care in the same law—this law encapsulates the Preborn Child Protection Act, severely restricting abortion, and the Let Them Grow Act, banning all gender-affirming care).

⁴² ch. 68, sec. 5, 2023 Colo. Sess. Laws at 243 (codified at Colo. Rev. Stat. § 12-30-121(1)(e) (2023)).

⁴³ art. 28, Ill. Pub. Act. 102-1117 (codified at 735 Ill. Comp. Stat. Ann. 40/28-10 (2023)).

⁴⁴ ch. 167, 2023 N.M. Laws; ch. 193, sec. 2, 2023 Wash. Sess. Laws.

⁴⁵ Mass. Ann. Laws ch. 12, § 111½; No. 14, 2023 Vt. Acts (codified at Vt. Stat. Ann. tit. 1, § 150(b) (2023)); No. 15, 2023 Vt. Acts (codified at Vt. Stat. Ann. tit. 1, § 150(b)).

⁴⁶ See *also* Conn. Pub. Acts No. 23-56 (grouping them together under “consumer health data”).

⁴⁷ Elayne J. Heisler, Evelyne P. Baumrucker, Vanessa C. Forsberg, Nathan James, Abigail F. Kolker, Patrick A. Landers, Bryce H. P. Mendez, Angela Napili, Hassan Z. Sheikh, Audrey Singer, Jared S. Sussman & Jessica Tollestrup, Cong. Rsch. Serv., R46785, Federal Support for Reproductive Health Services: Frequently Asked Questions 1–2 (2023), perma.cc/V9RA-LEU7.

⁴⁸ *Id.* at 1 (naming “contraception,” “abortion and abortion counseling,” “infertility-related services,” “maternity services,” and “reproductive health screening, preventative services, and treatment” as the other five types of reproductive health services).

⁴⁹ Natalie Ingraham & Israel Rodriguez, *Clinic Staff Perspectives on Barriers and Facilitators to Integrating Transgender Healthcare into Family Planning Clinics*, 7 *Transgender Health* 36, 41 (2022) (“[Reproductive and sexual health centers] viewed provision of transgender care as an obvious extension of that feminist health center lineage and work that honors their current mission statements—getting care to those who need it most.”).



care.⁵⁰ Some treatments labeled as “gender-affirming” or “transgender” health care are also prescribed to cisgender people.⁵¹

Limitations on Sharing

The Department should consider several further changes to narrow the sharing of data with law enforcement.

First, to better protect people’s PHI the Department should update the Privacy Rule to reflect current law and expectations of privacy and generally require a search warrant before a covered entity may disclose sensitive PHI to law enforcement. Currently, the Privacy Rule details how covered entities may disclose PHI upon receipt of several types of requests.⁵² These not only include warrants, but also requests that require less of a legal showing before seeking PHI.⁵³ This low-level process allows law enforcement to request and gain access to a patient’s PHI with little justification, even when the PHI is particularly revealing. Moreover, other forms of sensitive data, like the content of communications, require a higher level of process, namely a search warrant supported by probable cause.⁵⁴ PHI includes highly personal, sensitive information, and can impact privacy in similar ways as the content of communications, and should receive similar protections. We recommend the Department impose a warrant requirement for disclosure of PHI to law enforcement, with appropriate exceptions for less sensitive PHI (such as basic identifying information like a person’s name and address), emergencies, patient consent, and in other limited circumstances.

Second, to help ensure that law enforcement does not obtain a broad set of health data in connection with one investigation that it can then use in an abortion-related investigation, the Department should amend the existing Privacy Rule to ensure that any request for PHI is narrowly tailored and explicitly states the specific and particular elements within a health record that are necessary to the law enforcement investigation for which it is sought. Narrow and limited requests for non-reproductive health care PHI reduce the chance of data outside the scope of an investigation being shared and potentially used for other purposes, including unrelated abortion investigations and prosecutions.

⁵⁰ Kristyn Brandi & Puneet Gill, *Abortion Restrictions Threaten All Reproductive Health Care Clinicians*, 113 Am. J. Pub. Health (2023); Irin Carmon, *The Shared Anti-Trans and Anti-Abortion Playbook*, N.Y. Mag. (Apr. 4, 2023), perma.cc/B5WH-ZBH6.

⁵¹ See, e.g., *General Approaches to Medical Management of Menstrual Suppression*, Am. Coll. Of Obstetricians & Gynecologists (Sept. 2022), perma.cc/3JNA-R7RW.

⁵² 45 C.F.R. § 164.512(f)(1)(ii).

⁵³ For example, 45 C.F.R. § 164.512(f)(1)(ii)(B) permits sharing upon receipt of a grand jury subpoena and 45 C.F.R. § 164.512(f)(1)(ii)(C) permits sharing upon receipt of administrative request.

⁵⁴ See *United States v. Warshak*, 631 F.3d 266 (6th Cir. 2010) (holding emails are protected by the Fourth Amendment and require a warrant—this ruling has been accepted by the Department of Justice and major tech companies have since treated it as the law of the land).



For similar reasons, the Department should ensure that PHI shared pursuant to the law enforcement exception is not used for purposes beyond the specific investigation for which it was obtained. There is already precedent for limits like these. For example, the collection of drug addiction treatment information is barred from use for narcotics enforcement.⁵⁵ Any new rule must not create unintended backdoors for PHI to be repurposed and used in prosecutions related to reproductive health care that is lawful under the circumstances in which it is provided.

Attestations

CDT supports the attestation requirement for law enforcement seeking PHI potentially related to reproductive health care. However, additional provisions regarding monitoring and enforcement are necessary to ensure their efficacy.

To strengthen the attestation provisions, the Department must do more to ensure that attestations are truthful. For example, the Department can require any attestation made pursuant to the rule include a signed declaration made under penalty of perjury that the requester is not requesting PHI for any prohibited purpose. Such an inclusion can deter false attestations and also prohibit evidence obtained through such a system from being admissible in any legal proceeding.

The Department should also consider ways to audit attestations to ensure law enforcement officers uphold their promise not to use data contrary to the rule. This burden should fall primarily on the Department and on law enforcement rather than health care providers or patients themselves. The Department, in conjunction with other federal agencies, including the Department of Justice, should develop a robust oversight program to ensure that any attestations made pursuant to the rule are truthful and do not result in unpermitted uses of PHI for investigations related to reproductive health care that is lawful under the circumstances in which it is provided.

The Department should consider requiring law enforcement attestations to include a commitment from the requester that they will retain PHI only for the duration of the specific, articulated investigation and any prosecution and appeals. After the investigation and any appeals have concluded, law enforcement should delete the data. Such limits prevent PHI from being kept indefinitely and subsequently used for other purposes outside the scope of the original, limited purpose.

⁵⁵ 42 C.F.R. § 2 and its component parts (Part 2) addresses the confidentiality of substance use disorder patient records. Part 2 is designed to ensure that a patient receiving treatment for a substance use disorder will not face adverse criminal consequences for seeking treatment.

Last, the Department should strongly consider a standardized, model attestation for all requests.⁵⁶ The model should include clear language regarding the limited uses of any PHI that is shared, clearly outline the penalties for misuse, and require the investigating law enforcement entity to attest that any PHI shared will not be used in a criminal, civil, or administrative investigation into or proceeding against any person in connection with seeking, obtaining, providing, or facilitating reproductive health care that is lawful under the circumstances in which it is provided.

Standard forms will also reduce the burden on covered entities.⁵⁷ Standardization makes it easy for covered entities to review and ensure that attestations are sufficient before any PHI is shared. Moreover, standard forms allow law enforcement entities to use a unified form that not only outlines the information necessary to complete an attestation, but also permits the Department to include robust and complete explanations of what type of PHI can be sought, what permissible uses are, and the penalties for misuse or misleading or false attestations. Finally, enforcement efforts are more effective when using a standardized form. If everyone is required to use the same attestation forms, it will be easier to identify misuse and inappropriate requests for data.

Post-Rule Education

The Department should invest in robust education efforts to ensure that law enforcement departments and covered entities know the contours and limitations of the new rule. This guidance should include clear discussions and examples regarding impermissible uses of PHI in criminal, civil, or administrative investigations in connection with reproductive health care. For example, most people under court surveillance are subject to travel restrictions,⁵⁸ so the

⁵⁶ See, e.g., U.S. Dep't of Just., Guidance for Department Attorneys Regarding Student Loan Bankruptcy Litigation app. (2022) (Appendix A – Attestation Form 2023); Secure Software Development Attestation Common Form, 88 Fed. Reg. 25670 (proposed Apr. 27, 2023), perma.cc/BUW7-LTMN.

⁵⁷ A standard form would lessen the first of the six quantifiable costs the Department identified in the NPRM. See HIPAA Privacy Rule To Support Reproductive Health Care Privacy, 88 Fed. Reg. at 23540.

⁵⁸ Notably, every one of the 28 states that bans or places severe restrictions on abortions prior to 24 weeks LMP also restricts the travel of people under court surveillance in ways that could be dangerous to someone needing reproductive health care, including travel prohibitions during the first 60 days to six months of supervision, requirements to request permission to travel up to 30 days in advance, and denial of travel due to financial obligations—all states leave the person vulnerable to the decision of an officer. See, e.g., Ga. Code Ann. § 16-12-140 (2023), perma.cc/8PFM-5XXB; Living Infants Fairness and Equality Act, 2019 Ga. Laws 712, perma.cc/R9CX-EPDX; *Restrictions for Georgia*, Prob. Info. Network, perma.cc/K8KH-5EJY (Nov. 11, 2022, 3:38 PM); Idaho Code §§ 18-605, 18-606, 18-8804, perma.cc/PY7N-GM3T; *Restrictions for Idaho*, Prob. Info. Network, perma.cc/2C5J-CJNE (Nov. 11, 2022, 3:40 PM); Miss. Code Ann. § 41-41-45, perma.cc/NX6A-2SB6 (2023); Miss. Code Ann. § 97-3-3, perma.cc/ZR92-5KZY; *Restrictions for Mississippi*, Prob. Info. Network, perma.cc/PU2N-DC2V (Nov. 11, 2022, 3:48 PM); S.D. Codified Laws § 22-17-5.1; *Restrictions for South Dakota*, Prob. Info. Network, perma.cc/9856-JK2K (Nov. 11, 2022, 4:00 PM); Tex. Health & Safety Code §§ 170A.001-7, 170A.004; *Restrictions for Texas*, Prob. Info. Network, perma.cc/9XFJ-24ST (Nov. 11, 2022, 4:01 PM).



guidance must be clear that their PHI⁵⁹ cannot be solicited or used secondarily for investigations or proceedings related to their obtaining of lawful reproductive health care, including investigations or proceedings related to out-of-state travel for care.⁶⁰

IV. Conclusion

We commend the Department for undertaking this important and critically necessary work. Current regulations fail to adequately ensure that PHI will not be used as evidence in criminal proceedings related to legal treatments. The provisions proposed in the NPRM go a long way to address several key concerns. The amendments proposed above will better protect patients, increase trust between patients and providers, and result in better overall health outcomes. We look forward to working with OCR throughout this process.

⁵⁹ It is important to recognize that people with ankle monitors' privacy is already compromised through the monitors' ability to send law enforcement continuous geolocation and audio recordings—features that can put people seeking reproductive health care at incredible risk. Kate Weisburd, *Op-Ed: Women in prison and under court surveillance will suffer under new abortion bans*, L.A. Times (July 5, 2022), perma.cc/6C5B-JMUX; see also Nila Bala & Lars Trautman, *A Wearable Wiretap*, Slate (Nov. 8, 2019, 8:30 AM), perma.cc/5NLT-3MCH; see, e.g., Kira Lerner, *Chicago is Tracking Kids with GPS Monitors that Can Call and Record Them Without Consent*, Appeal (Apr. 8, 2019), perma.cc/6U2B-XGJ3; Joshua Kaplan, *D.C. Defendants Wear Ankle Monitors That Can Record Their Every Word and Motion*, Wash. City Paper (Oct. 8, 2019), perma.cc/GD4U-7H6C. Cf. Saira Hussain & Will Greenberg, *Study of Electronic Monitoring Smartphone Apps Confirms Advocates' Concerns of Privacy Harms*, Electronic Frontier Found. (Sept. 23, 2022), perma.cc/9QA9-TU25; Sidney Fussell, *Apps Are Now Putting the Parole Agent in Your Pocket*, Wired (Nov. 11, 2020, 7:00 AM), perma.cc/D7PZ-C7XM.

⁶⁰ See Wanda Bertram & Wendy Sawyer, *What the end of Roe v. Wade will mean for people on probation and parole*, Prison Pol'y Initiative (June 30, 2022), perma.cc/SVF7-Y7NE; Weisburd, *supra* note 59.