

June 16, 2023

VIA ELECTRONIC TRANSMISSION

Melanie Fontes Rainer
Director, Office for Civil Rights
Department of Health and Human Services
200 Independence Avenue, SW
Room 509F, HHH Building
Washington, D.C. 20201

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

Dear Director Fontes Rainer:

Thank you for the opportunity to comment in response to the Notice of Proposed Rulemaking (proposed rule, NPRM), “HIPAA Privacy Rule To Support Reproductive Health Care Privacy,” released by the Department of Health and Human Services (HHS or the Department) Office for Civil Rights (OCR) on April 12, 2023 and published in the Federal Register on April 17, 2023.¹ The 125 groups signed on here represent members of the reproductive rights and justice and consumer advocacy communities, as well as reproductive and other health care providers, research organizations, health care advocacy groups, and civil rights and other allied organizations.

I. This Proposed Rule is an Important Step Toward Strengthening Privacy Protections, Improving Trust between Patients and Providers, and Promoting High-Quality Care

We appreciate that HHS OCR has proposed modifications to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule to strengthen essential protections for protected health information (PHI) in order to safeguard access to and quality of reproductive health care. Following the Supreme Court’s decision in *Dobbs v. Jackson Women’s Health Organization* (*Dobbs*), this proposed rule takes a critical step in the right direction to protect the security of reproductive health care information in light of the serious risk of criminalization facing providers and patients.

People with the capacity for pregnancy have long been subject to surveillance and criminalization related to pregnancy and abortion. New analysis shows that one of the largest driving forces for criminalization related to pregnancy status or outcomes is health care providers unnecessarily reporting their patients to law enforcement.²

¹ 88 Fed. Reg. 23506-23553 (Apr. 17, 2023).

² Laura Huss, et al., *Self-Care, Criminalized: August 2022 Preliminary Findings*, If/When/How: Lawyering for Reproductive Justice, <https://www.ifwhenhow.org/resources/self-care-criminalized-preliminary-findings> (finding that 45 percent of adult cases came to the attention of law enforcement through care providers, including health care providers and social workers); Lynn M. Paltrow & Jeanne Flavin, *Arrests of and Forced Interventions on Pregnant*

Members of historically underserved communities, including communities of color, are more likely to be subjects of investigations and proceedings related to reproductive health care. Alarming, but unsurprisingly, low-income, Black, and brown women comprise the majority of people subjected to criminal proceedings arising from their pregnancies – a significant disparity when compared to their white counterparts.³ The consequences of any entanglement with the criminal system (including arrest, prosecution, detention, and/or conviction) are far-reaching, especially for women of color, as they can further compound existing harms of poverty and systemic racism.⁴

Importantly, the same communities subject to increased levels of surveillance and criminalization are also the least likely to have equitable access to health care⁵ and the most likely to experience poor health outcomes.⁶ There is an entrenched mistrust between Black and brown patients and the health care system stemming from the history of reproductive health care experiments, forced sterilization, and ongoing discrimination and mistreatment.⁷ Criminalizing pregnant people exacerbates this mistrust and intensifies health inequities. If individuals fear their PHI will be disclosed without their knowledge or consent, they could be less likely to seek out health care and unlikely to be forthcoming about their symptoms, medical history, and other relevant information.

Since the *Dobbs* decision, the specter of criminalization has increased significantly, for both patients and providers. People must feel – and actually be – safe while accessing health care, but the overturning of *Roe v. Wade* further erodes this very necessary trust between patients and providers.⁸

II. Testing and Treatment for Substance Use in the Perinatal Period Must Explicitly Be Recognized as Included Within Reproductive Health Care and Therefore Covered by the Rule

We urge the Department to clarify in explicit terms that its definition of “Reproductive Health Care” includes drug testing, drug screening, and treatment for substance use disorders throughout

Women in the United States, 1973–2005: Implications for Women's Legal Status and Public Health, 38 J. Health Pol., Pol'y, & L. 299 (Apr. 2013), <https://doi.org/10.1215/03616878-1966324>.

³ Paltrow & Flavin, *supra* note 2; Sandhya Dirks, *Criminalization of Pregnancy has already been Happening to the Poor and Women of Color*, NPR (Aug. 3, 2022), <https://www.npr.org/2022/08/03/1114181472/criminalization-of-pregnancy-has-already-been-happening-to-the-poor-and-women-of>.

⁴ Pregnancy Justice, *Confronting Pregnancy Criminalization: A Practical Guide for Healthcare Providers, Lawyers, Medical Examiners, Child Welfare Workers, and Policymakers* (July 2022), <https://www.pregnancyjusticeus.org/wp-content/uploads/2022/12/202211-PJ-Toolkit-Update-2.pdf>.

⁵ Sinsi Hernández-Cancio & Venicia Gray, *Racism Hurts Moms and Babies*, National Partnership for Women & Families (2021), <https://www.nationalpartnership.org/our-work/resources/health-care/racism-hurts-moms-and-babies.pdf>.

⁶ National Partnership for Women & Families, *Maternity Care in the United States: We Can – and Must – Do Better* (Feb. 2020), <https://www.nationalpartnership.org/our-work/resources/health-care/maternity-care-in-the-united.pdf>.

⁷ Susan Rinkunas, *Doctors and Nurses Shouldn't Be Able to Report Your Pregnancy Loss to the Police*, Jezebel (Feb. 13, 2023), <https://jezebel.com/does-hipaa-law-protect-information-about-abortion-1850108057>.

⁸ Data for Progress (last visited June 14, 2023), https://www.filesforprogress.org/datasets/2022/12/dfp_disability_reproductive_privacy.pdf.

the perinatal period. The practice of drug testing pregnant people and reporting the results of those tests to state authorities is the leading reason why pregnant people face criminalization and other punitive state actions due to their pregnancy status or outcomes.⁹ In the years since *Roe* was decided in 1973, Pregnancy Justice has documented over 1,700 instances across the country in which women were arrested, prosecuted, convicted, detained, or forced to undergo medical interventions that would not have occurred but for their status as pregnant persons whose rights state actors assumed could be denied in the interest of fetal protection.¹⁰ In all of these cases of pregnancy criminalization, being pregnant was a necessary element of the crime or a “but for” reason for the coercive or punitive action taken. Between 1973 and 2005, 413 such cases were brought, whereas between 2006 and 2020, over 1,331 such cases were brought, indicating that the rate of pregnancy criminalization is rapidly increasing.¹¹

Over eighty-four percent of the arrests and prosecutions identified involved allegations of the use of controlled substances, even though the vast majority of state criminal laws do not make using drugs—as opposed to possessing drugs—illegal. Accordingly, these prosecutions sought to transform drug use or dependency by one group of people—pregnant women—into criminal “child abuse,” “chemical endangerment” or even “murder.”¹² Moreover, at least forty-one percent of these cases originated from reports from health care providers or hospital social workers, indicating that the prosecutions would never have been brought were it not for the common practice of nonconsensual drug testing and reporting.¹³

Drug testing perinatal patients without a specific medical concern and without their informed consent is widely opposed by leading medical organizations.¹⁴ For instance, the American College of Obstetricians and Gynecologists (ACOG) provides, “[T]esting and reporting puts the therapeutic relationship between the obstetrician–gynecologist and the patient at risk, potentially placing the physician in an adversarial relationship with the patient.”¹⁵ In addition to eroding patient-provider trust, ACOG recognizes that testing and “reporting during pregnancy may dissuade women from seeking prenatal care and may unjustly single out the most vulnerable, particularly women with low incomes and women of color.”¹⁶ ACOG concludes that “[d]rug enforcement policies that deter women from seeking prenatal care are contrary to the welfare of the mother and fetus.”¹⁷

⁹ Paltrow & Flavin, *supra* note 2 at 299.

¹⁰ Pregnancy Justice, *Arrests and Deprivations of Liberty of Pregnant Women, 1973-2020* (Sept. 2021), <https://www.pregnancyjusticeus.org/arrests-and-prosecutions-of-pregnant-women-1973-2020/>.

¹¹ *Id.*

¹² Paltrow & Flavin, *supra* note 2 at 323.

¹³ *Id.* at 311.

¹⁴ See American College of Obstetrics and Gynecologists, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period* (Dec. 2020), <https://www.acog.org/clinical-information/policy-and-position-statements/statements-of-policy/2020/opposition-criminalization-of-individuals-pregnancy-and-postpartum-period>;

¹⁵ American College of Obstetricians and Gynecologists, *ACOG Committee Opinion: Substance Abuse Reporting and Pregnancy: The Role of the Obstetrician–Gynecologist* (reaffirmed 2022), <https://www.acog.org/clinical/clinical-guidance/committee-opinion/articles/2011/01/substance-abuse-reporting-and-pregnancy-the-role-of-the-obstetrician-gynecologist>.

¹⁶ *Id.*

¹⁷ *Id.*; see also American College of Obstetricians and Gynecologists, *supra* note 14 (“Criminalization of pregnant people for actions allegedly aimed at harming their fetus poses serious threats to people’s health and the health system itself. Threatening patients with criminal punishment erodes trust in the medical system, making people less likely to seek help when they need it.”).

Indeed, the consequences of drug testing, reporting, and criminalizing pregnant people for substance use extend far beyond the individual person investigated. When pregnancy and substance use are subject to prosecution and candid communications with health care providers are used as the basis for child welfare and law enforcement actions, pregnant people are deterred from seeking medical care and supportive services that would improve pregnancy outcomes.¹⁸ For example, research revealed that the prosecution of women for pregnancy and substance use under Tennessee’s fetal assault law (which was in effect for only two years) resulted in twenty fetal deaths and sixty infant deaths in 2015 alone.¹⁹

The Department must clarify that its definition of “Reproductive Health Care” encompasses testing for and treatment of substance use throughout the perinatal period to guard against this common pathway to pregnancy criminalization. The omission of drug testing and treatment during the perinatal period from the current definition of “Reproductive Health Care” risks the further erosion of patient-provider trust and will deter the most vulnerable pregnant people from seeking necessary medical care.

III. The Protections of the Rule Must Extend to Self-Managed Abortion

The proposed rule does not go far enough to protect patients who may have self-managed an abortion or who are suspected of doing so. The inclusion of the word “lawful” in front of “reproductive health care” will perpetuate continued misunderstanding and misapplication of the law by health care providers and law enforcement alike. The term incorrectly suggests that *receiving* abortion care may be unlawful, whereas most prohibitions on abortion apply to providing or performing the abortion. Except under rare circumstances, discussed below, it is not a crime to receive abortion care or self-manage one’s abortion;²⁰ however, abortion-seekers face risks of criminalization when health care providers misunderstand the law. We suggest eliminating this unnecessary term that would only perpetuate continued misunderstanding and misapplication of the law.

There are no laws that would require a report to law enforcement by a health care provider concerning a self-managed abortion.²¹ However, confusion about reporting requirements and anti-abortion sentiment causes unnecessary reports, which all too frequently lead to investigation

¹⁸ See Rebecca L. Haffajee, et al., *Pregnant Women with Substance Use Disorders—The Harm Associated with Punitive Approaches*, 384 N. Engl. J. Med. 2364 (2021); Laura J. Faherty, et al., *Association of Punitive and Reporting State Policies Related to Substance Use in Pregnancy with Rates of Neonatal Abstinence Syndrome*, JAMA Open Network (2019), <https://jamanetwork.com/journals/jamanetworkopen/fullarticle/2755304>.

¹⁹ Meghan Boone & Benjamin J. McMichael, *State-Created Fetal Harm*, 109 Georgetown L. J. 475, 514 (2021).

²⁰ Self-managed abortion is an abortion that takes place outside of a formal medical setting. Though many self-managed abortions occur utilizing medication abortion – mifepristone and misoprostol, or misoprostol alone – people also use botanical methods, massage, and sometimes unsafe methods of self-managing. Only Nevada and South Carolina have statutes that explicitly make it a crime to self-manage an abortion. Nev. Rev. Stat. § 200.220; S.C. Code Ann. § 44-41-80(b). Though currently enjoined, South Carolina’s recent six-week ban would repeal this statute. S.C. Code Ann. § 44-41-730; *Planned Parenthood South Atlantic, et al. v. South Carolina, et al.*, Court of Common Pleas for the 5th Judicial Circuit, C/A No.: 2023-CP-40-002745 (May 26, 2023).

²¹ *Patient Confidentiality and Self-Managed Abortion: A Guide to Protecting Your Patients and Yourself*, If/When/How: Lawyering for Reproductive Justice (2020), available at <https://tinyurl.com/MandatoryReportingFactSheets>.

and arrest, even though no crime has been committed. A study from If/When/How, cited in the proposed rule, indicates that 45% of self-managed abortion criminal cases stem initially from a report to law enforcement by a health care provider.²² We have reason to believe, based on If/When/How's cases and inquiries to If/When/How's Repro Legal Helpline since the overturn of *Roe*, that the frequency of abortion-related reports to law enforcement specifically by health care providers has increased. Patients report that the health care professionals who care for them have stated that they must report their abortion to law enforcement. Though some would-be reports are thwarted by the intervention of other staff or administrators in the hospital setting, not all are prevented. Part of the confusion about reporting is that some health care professionals believe they are legally obligated to report a suspected crime, even where no such reporting requirement exists, or when the activity is not a crime. And in the two states where self-managed abortion is prohibited (South Carolina and Nevada²³), health care providers may feel pressured or obligated to report it to law enforcement – even though no such requirement exists.

IV. Extending the Proposed Rule's Protections to Other Forms of Health Care

Given the current landscape following the *Dobbs* decision, we understand the Department's focus on reproductive health care in the proposed rule. At the same time, we appreciate the Department specifically asking for comment on whether to extend the proposed prohibited uses and disclosures to other forms of health care. We strongly believe that health care providers should never be in the business of policing, or facilitating the criminalization of, their patients, regardless of the type of health care they are seeking. We also know that there are particular forms of health care that are closely analogous to the reproductive health care context - these forms of care have been similarly criminalized, are often stigmatized or seen as highly sensitive, and are types of care where improving trust between patients and providers is of paramount importance. Most notably, there has been a significant increase in laws prohibiting transgender health care (also known as gender-affirming care) for both children and adults. Many, if not all, of the concerns that the preamble identifies as a consequence of *Dobbs* and state laws banning reproductive health care are also applicable to state laws banning transgender health care. Similar concerns may also arise in the context of other forms of health care, including but not limited to mental health care and substance use disorder treatment. Consequently, we urge the Department to consider broadening the scope of this rule to other forms of health care.

V. Strengthening the Attestation Provision and Ensuring Robust Enforcement

While we appreciate the administration's proposal to add a requirement to obtain an attestation from the person requesting the use and disclosure of PHI as a condition for certain permitted uses and disclosures, we believe that this provision needs to be strengthened and robust enforcement of HIPAA protections must be prioritized.

Even though the Department rightly notes that a requester who "knowingly falsifies an attestation . . . could be subject to criminal penalties," that may not deter requesters, including law enforcement, from making false claims, especially since the Department is not requiring a regulated entity to investigate the validity of the attestation. In turn, we ask that the Department

²² Huss, et al., *supra* note 2.

²³ Nev. Rev. Stat. § 200.220; S.C. Code Ann. § 44-41-80(b).

require the attestation to include a signed declaration made under penalty of perjury that the requester is not making the request for a prohibited purpose.

In addition, we hope that the administration will do more to strongly enforce the attestation provision and create a process to ensure that the attestations are not abused. This could include offering grants for provider education and training, creating a helpline for covered entities to ask questions about what is and is not prohibited under HIPAA and how to determine whether an attestation is objectively reasonable, and providing legal and technical support to covered entities that are reviewing attestations. We are also in favor of the Department developing a model attestation that a regulated entity may use when developing its own attestation template.

VI. Further Clarity as to the Scope of the Rule Would Be Beneficial

Health care providers should never proactively share personal health information of their patients. As discussed above, visits to a provider to seek pregnancy care or for delivery can be entry points into the criminal legal system for parents and into state custody for children. These referrals occur in myriad ways: clinicians call authorities when a patient refuses to consent to a medical procedure during prenatal care or childbirth, when the patient herself is in foster care, when the patient has a child who has prior foster-system involvement, when the patient is incarcerated, or when the patient has a disability.

The laws of the states are changing and evolving and a presumption against disclosures will protect patients and accommodate various state approaches. The American College of Obstetricians and Gynecologists (ACOG) notes that the use of the legal system to address perinatal alcohol and substance abuse is inappropriate and that physicians should work together to rescind punitive legislation and identify and implement evidence-based strategies outside the legal system to address the needs of patients.²⁴ In the context of abortion, ACOG states that “it is essential that obstetrician–gynecologists and other clinicians protect patient autonomy, confidentiality, and the integrity of the patient–clinician relationship.” Other professional medical organizations have similar positions - the role of the clinician is to provide care, not police their patients.

It would be beneficial to further clarify or provide additional examples of instances in which the use or disclosure of PHI would be permitted under the privacy rule, including examples of types of investigations or proceedings that are focused on health care fraud and for which PHI is necessary.

VII. Conclusion

We applaud OCR for proposing this rule to strengthen privacy and protect access to reproductive health care, and we appreciate the opportunity to highlight our views and concerns. We look forward to continuing to work with the Department to ensure trust between patients and providers and promote equitable access to care.

²⁴ American College of Obstetricians and Gynecologists, *supra* note 15.

Sincerely,

National Organizations

A Better Balance: The Work & Family Legal Center
Abortion Access Front
Abortion Care Network
Abortion Freedom Fund
Abortion on Demand
ACA Consumer Advocacy
Academy of Perinatal Harm Reduction
American Association of University Women
American Federation of Teachers
American Humanist Association
American Medical Student Association (AMSA)
American Society for Emergency Contraception
Apiary for Practical Support
Autistic Self Advocacy Network
Caring Across Generations
The Center for HIV Law & Policy (CHLP)
Center for American Progress
Center for Law and Social Policy (CLASP)
Center for Popular Democracy
Community Catalyst
Drug Policy Alliance
Electronic Frontier Foundation
Elephant Circle
Equal Rights Advocates
Families USA
Grandmothers for Reproductive Rights (GRR!)
Guttmacher Institute
Hadassah, The Women's Zionist Organization of America
If/When/How: Lawyering for Reproductive Justice
Ipas
Jacobs Institute of Women's Health
Jewish Women International
Lawyering Project
The Leadership Conference on Civil and Human Rights
Legal Momentum, The Women's Legal Defense and Education Fund
Medical Students for Choice
MYA Network
NARAL Pro-Choice America
National Abortion Federation
National Alliance to End Sexual Violence
National Association of Pediatric Nurse Practitioners
National Center for Lesbian Rights
National Council of Jewish Women

National Disability Rights Network (NDRN)
The National Domestic Violence Hotline
National Employment Law Project
National Family Planning & Reproductive Health Association
National Health Law Program
National Institute for Reproductive Health
National Latina Institute for Reproductive Justice
National League for Nursing
National Network of Abortion Funds
National Partnership for Women and Families
National Perinatal Association
National Urban League
National Women's Law Center
NMAC (National Minority AIDS Council)
Nurses for Sexual & Reproductive Health
Physicians for Reproductive Health
Planned Parenthood Federation of America
Positive Women's Network-USA
Pregnancy Justice
Reproaction
Reprocare
Reproductive Health Access Project
Reproductive Justice Inside
RH Impact: The Collaborative for Equity & Justice
SAGE
Sexual Violence Prevention Association (SVPA)
SIECUS: Sex Ed for Social Change
Southern Poverty Law Center
State Innovation Exchange (SiX)
UCSF Bixby Center for Global Reproductive Health
Union for Reform Judaism
URGE: Unite for Reproductive & Gender Equity
USOW
We Testify
Women of Reform Judaism

Regional and State Organizations

A Woman's Choice Clinics: Jacksonville, Charlotte, Greensboro, Raleigh, FL and NC
ACT Access, NY
Advancing New Standards in Reproductive Health (ANSIRH) at UC San Francisco, CA
All Families Healthcare, MT
Atlanta Women's Center, GA
California Academy of Family Physicians, CA
California Nurse-Midwives Association, CA
Camelback Family Planning, AZ
CARE Colorado, CO

Cherry Hill Women’s Center, NJ
CHOICES Center for Reproductive Health, IL and TN
Choix, CA, CO, IL, ME, NM, and VA
Cobalt Abortion Fund, CO
Delaware County Women’s Center
Essential Access Health, CA
Faith Choice Ohio, OH
Freedom BLOC, OH
Fund Texas Choice, TX
Gloucester County NAACP, NJ
Hartford GYN Center, CT
HEAL Ohio, OH
Health Care for the Homeless, MD
Jane’s Due Process, TX
Just the Pill/Abortion Delivered, CO, MN, MT, and WY
Legal Voice, WA
Louisiana Coalition for Reproductive Freedom, LA
Maryland NOW, MD
National Council of Jewish Women, New Jersey Sections, NJ
North Jersey Practical Support, NJ
Peer Network of New York, NY
Philadelphia Women’s Center, PA
Planned Parenthood Southeast, AL, GA, and MS
Pro-Choice North Carolina, NC
Unitarian Universalist Faith Action, NJ
The Women’s Law Center of Maryland, MD
Women’s Law Project, PA
Young Democrats of Maryland Women’s Caucus, MD

Local Organizations

Austin Women’s Health Center, Austin, TX
Cambridge Health Alliance, Cambridge, MA
Family Planning Associates Medical Group, Phoenix, AZ
Housing Works, New York, NY
Impetus – Let’s Get Started LLC, St. Paul, MN
LifeLong Medical Care, Berkeley, CA
Northland Family Planning Centers, Southland, Sterling Heights, and Westland, MI
Pacific Asian Counseling Services, Los Angeles, CA
Partners in Abortion Care, College Park, MD
Washington Surgi-Clinic, Washington, DC