

June 16, 2023

VIA ELECTRONIC SUBMISSION

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:

Physicians for Reproductive Health (PRH) is pleased to have the opportunity to submit comments to the Department of Health and Human Services (the Department) on the HIPAA Privacy Rule to Support Reproductive Health Care Privacy. PRH is a physician-led national advocacy organization that organizes, mobilizes, and amplifies the voices of medical providers across the United States to advance sexual and reproductive health, rights, and justice. Our programs combine education, advocacy, and strategic communications to ensure access to the full spectrum of equitable, comprehensive reproductive health care. We believe that this work is necessary for all people to live freely with dignity, safety, and security.

PRH greatly appreciates the Department's acknowledgement of the importance of privacy for reproductive health care, especially in the wake of the Supreme Court's decision in *Dobbs v. Jackson Women's Health Organization*. Even prior to this ruling, as states began to significantly limit or criminalize abortion, we have seen individuals' protected health information (PHI) used against them for investigations or proceedings. This has worsened in the year following the ruling as antichoice legislators and prosecutors attempt to punish people for seeking or providing abortion care. This has had a chilling effect on access to comprehensive reproductive health care and threatens the trust that is foundational to the patient-provider relationship. The proposed modifications to the Privacy Rule to avoid its use for a disclosure of PHI as a pretext for obtaining sensitive information for a non-health care context will help protect both the safety and privacy of patients and allow providers to honor their oaths to keep information private unless disclosure is explicitly requested by the person they are caring for.

As the Department notes in the NPRM, “a positive, trusting relationship between individuals and their health care providers is essential to an individual’s health and well-being.”<sup>1</sup> This ideal, however, has not been actualized in many communities. The deep mistrust and distrust that many communities of color have for health care systems is a result of centuries of historical and active harm at the hands of medical practitioners and health authorities. This deep mistrust affects people’s willingness to seek medical care and share their personal health information. Avoiding or delaying care and sharing incomplete health information can negatively impact health outcomes, worsening existing health inequities. The proposed modifications a critical step in addressing these concerns and safeguarding patients accessing care.

### **Protecting PHI Concerning Self-Managed Abortion**

Even before *Roe v. Wade* was overturned, people faced criminalization for their pregnancy outcomes, including abortion. If/When/How: Lawyering for Reproductive Justice identified 61 cases over 20 years in 26 states of people criminally investigated or arrested for allegedly ending their own pregnancies or helping someone to do so.<sup>2</sup> Cases were most often brought to law enforcement by health care providers and social workers after individuals sought care. Even if charges are not filed, an investigation by law enforcement or a government agency is traumatic and can have far-reaching consequences. It is essential for health care providers to understand their obligations under the law to safeguard PHI.

The proposed modification to the Privacy Rule would prohibit a regulated entity under HIPAA from using or disclosing an individual’s PHI “for the purpose of conducting a criminal, civil, or administrative investigation into or proceeding against a health care provider, or other person in connection with seeking, obtaining, providing, or facilitating reproductive health care” where the care is “lawful.” While we support this premise, PRH suggests eliminating the word “lawful” as it is confusing and unnecessary.

The discussion section states that the Privacy Rule would not permit a disclosure “where state law does not expressly require reporting of suspicions of self-managed reproductive health care.” The inclusion of this text is confusing since there are currently no states that require reports to law enforcement about self-managed abortion.<sup>3</sup> Only two states, South Carolina<sup>4</sup> and Nevada, prohibit self-managed abortion and neither of those states obligate providers to report suspected self-managed abortions to authorities. Just because a person chooses to self-

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<sup>1</sup> 88 Fed Reg 73 (April 17, 2023), available at <https://www.federalregister.gov/documents/2023/04/17/2023-07517/hipaa-privacy-rule-to-support-reproductive-health-care-privacy>.

<sup>2</sup> Self-Care, Criminalized: August 2022 Preliminary Findings, Laura Huss, Farah Diaz-Tello, & Goleen Samari, available at file:///C:/Users/jblasdell/Downloads/22\_08\_SMA-Criminalization-Research-Preliminary-Release-Findings-Brief\_FINAL.pdf.

<sup>3</sup> *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>.

<sup>4</sup> South Carolina’s recently passed six-week abortion ban (which is currently enjoined by the courts) would repeal this provision.

manage their abortion does not automatically mean that it is unlawful. In fact, many statutes banning or limiting abortion care specifically exempt the pregnant person. Deleting the lawful terminology and altering the example will help clarify that providers should not feel pressured to report a self-managed abortion to law enforcement and clarify that this reporting is a violation of privacy protections.

### **Definition of Reproductive Health Care**

HHS has asked for comments on the scope of the draft rule including the definition of “reproductive health care.” Reproductive health care is a broad spectrum of services and needs to be understood as such. While the country has understandably focused on abortion access since the Supreme Court eliminated the constitutional right to abortion, all aspects of reproductive health care deserve protection and many people have been criminalized for seeking health care services beyond abortion care.

The NPRM notes that members of law enforcement have sought to obtain PHI “for use against pregnant individuals on the basis of their pregnancy status or pregnancy outcomes.” For example, the common practice of drug testing pregnant people and reporting positive test results to authorities can also lead to criminalization of pregnant people and punitive actions such as arrest or family separation.<sup>5</sup> Pregnancy Justice has documented over 1,700 instances nationwide since 1973 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. An alarming 84% of these arrests and prosecutions involved allegations of substance use even though most criminal codes do not make using drugs illegal.<sup>6</sup> Eighty-six percent of the prosecutions studied by Pregnancy Justice applied existing criminal statutes intended for other purposes such as child abuse or child endangerment.

The American College of Obstetricians and Gynecologists (ACOG) notes that criminalizing pregnant people for actions that the state alleges harms a fetus poses serious threats to people’s health.<sup>7</sup> ACOG points out that “bias and racism play a role in discriminatory behavior when determining who and when to test or report.”<sup>8</sup> Black and Indigenous women seeking

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<sup>5</sup> Lynn M. Paltrow & Jeanne Flavin, *Arrests of and Forced Interventions on Pregnant 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://read.dukeupress.edu/jhpl/article/38/2/299/13533/Arrests-of-and-Forced-Interventions-on-Pregnant>.

<sup>6</sup> Pregnancy Justice, *Arrests and Other Deprivations of Liberty of Pregnant Women, 1973-2020* (Sept. 2021), available at <https://www.pregnancyjusticeus.org/wp-content/uploads/2021/09/Arrests-of-Pregnant-Women-1973-2020-Fact-Sheet.pdf>.

<sup>7</sup> American College of Obstetrics and Gynecologists, *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*. (Dec. 2020), available at <https://www.acog.org/clinical-information/policy-and-position-statements/statements-of-policy/2020/opposition-criminalization-of-individuals-pregnancy-and-postpartum-period>.

<sup>8</sup> *Id.*

pregnancy are more likely to be screened for illicit substance use.<sup>9</sup> Such testing — often undisclosed and performed without explicit consent — has resulted in parents losing their children or being incarcerated.<sup>10</sup> This is particularly harmful for Black and Indigenous families because their children are more likely to be removed from their custody, turned over to the state, and left in the foster care system much longer than children of White families.<sup>11</sup> It is important to note that a drug test cannot determine the existence of a substance use disorder<sup>12</sup> and leading medical groups such as ACOG agree that a positive drug test should not be construed as child abuse or neglect.<sup>13</sup>

Screening, testing and treatment for substance use of people seeking reproductive health care should be considered a part of reproductive health care under the proposed rule and making this explicit by adding it to the definition of reproductive health care will help providers understand their role in safeguarding information and provide assurance to people seeking care.

### **Protecting Other Types of Highly Sensitive PHI**

The Department asks for comment about whether there should be prohibitions or limits on the uses or disclosures of “highly sensitive PHI.” When care is prohibited or limited, it becomes stigmatized. Abortion care is health care. It is normal, it is safe, and it is common. And yet it needs to be protected because of the criminal penalties, harassment, and even violence that is directed at providers of abortion care and their patients. Sadly, we are seeing these scenarios play out with other types of essential health care such as gender-affirming care as states impose criminal penalties and felony classifications, forcing patients to travel out of state for their care, move out of state so they can continue care, or tragically forego care all together.

Those who are HIV positive, unhoused, have unmet mental health needs or use substances that are criminalized have all been targeted while seeking or obtaining health care. This occurs because this care has been stigmatized and criminalized leading to heightened surveillance and policing, threatening their safety and well-being in their own communities. The Department should consider creating similar protections with these other communities in need in mind. The goals outlined in the draft rule also apply in other care contexts – making sure people do not fear punishment for seeking care and creating conditions for open conversations with their providers about their care.

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<sup>9</sup> Kunins HV, Bellin E, Chazotte C, Du E, Arnsten JH. *The effect of race on provider decisions to test for illicit drug use in the peripartum setting.* J Womens Health (Larchmt) 2007;16:245-255.

<sup>10</sup> Perritt, J. *#WhiteCoatsforBlackLives – Addressing Physicians’ Complicity in Criminalizing Communities,* November 5, 2020. N Engl J Med 2020; 383:1804-1806

<sup>11</sup> Roberts DE. *Prison, foster care, and the systemic punishment of Black mothers.* UCLA Law Rev 2012;59:1474-1500.

<sup>12</sup> Center for Substance Abuse Treatment. *Drug Testing in Child Welfare: Practice and Policy Considerations.* HHS Pub. No. (SMA) 10-4556 Rockville, MD: Substance Abuse and Mental Health Services Administration, 2010, available at <https://ncsacw.acf.hhs.gov/files/drugtestinginchildwelfare.pdf>.

<sup>13</sup> American College of Obstetricians and Gynecologists, *supra* note 7.

### **Inclusion of Additional Examples of Permitted Disclosures of PHI**

The Department asks if examples of the types of investigations or proceedings for which the use or disclosure of PHI would be permitted would be beneficial. PRH believes that clear and common examples of permitted and prohibited disclosures would be extremely helpful. Health care providers should always default to keeping their patients' information confidential and having clear guidance will help them and their institutions navigate the constantly evolving legal landscape for reproductive health care. If there is confusion or ambiguity about a situation, health care providers should err on the side of safeguarding their patients and not share their PHI. It is unconscionable that across the country providers are being asked to choose between their ethical obligations to provide care and complying with the unjust laws of their states. There is an ethical obligation to safeguard patients' information. We appreciate the Department's efforts to make sure that PHI is also protected by the law.

### **Attestation**

PRH supports adding a requirement to obtain an attestation from the person requesting the PHI. We hope the Department considers strengthening this requirement through robust enforcement, education about the rule, and technical assistance. As drafted, simply attesting that the use or disclosure of PHI is not prohibited would be complying with the rule. In this hostile environment, PRH is concerned that the attestation could be abused and that providers may be unclear when an attestation is inadequate or invalid. Having a strong attestation requirement will result in patients and their providers feeling secure in the safeguarding of PHI.

Overall, PRH strongly supports the important steps the Proposed Rule takes and welcomes the recognition that PHI in reproductive health care needs strong and clear protections. We emphasize that nobody should be criminalized or persecuted for seeking health care and that we must make every effort to safeguard PHI. Please do not hesitate to reach out Jennifer Blasdell, Vice President, Public Policy & Strategic Partnerships, [jblasdell@prh.org](mailto:jblasdell@prh.org), with any questions.

Sincerely,

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President & CEO  
Physicians for Reproductive Health