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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: Comments on the Proposed Rule on HIPAA Privacy Rule to Support Reproductive Health Care Privacy, RIN 0945-AA20

Submitted via [www.regulations.gov](http://www.regulations.gov)

Legal Momentum welcomes the opportunity to comment on the Department of Health and Human Services' (HHS) proposed rule, which would establish additional requirements around the sharing of protected health information (PHI) relating to patient initiated and provider administered reproductive health care.

Legal Momentum, the Women's Legal Defense and Education Fund, is the nation's first and longest serving legal advocacy organization dedicated to advancing gender equality for women. For more than 50 years, we have used strategic litigation, innovative public policy, and educational initiatives to ensure that all women are protected under the law. Among our primary focus areas is reproductive justice<sup>1</sup> and protecting pregnant persons from being penalized for their pregnancies and pregnancy outcomes. Through our cases and national Helpline, we have seen firsthand how the disclosure of pregnant patients' medical history triggers government surveillance, intrusive investigations, and family separation, negatively impacting pregnant persons and their families, particularly low-income families and families of color.

Legal Momentum submits these comments to express overall support for the HIPAA Privacy Rule to Support Reproductive Health Care Privacy. This rule will enhance privacy protections and cultivate trust within the patient-provider relationship by adding extra limitations to the use and disclosure of PHI for reproductive health care by protecting the privacy of individuals who obtain reproductive health care that is lawful under the circumstances in which it is provided, as well as their health care providers, and others who assist them in obtaining such health care. Additionally, we support the HHS' efforts to broadly define reproductive health care, but we suggest additional ways to expand the proposed rule's protections to ensure that it is inclusive and effective in safeguarding the rights of patients' reproductive health care and other forms of health care.

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<sup>1</sup> Legal Momentum has a long history of leading, and joining, amicus briefs protecting the right to reproductive freedom. We have appeared as amici in every leading reproductive rights case, including *Dobbs v. Jackson Women's Health Organization*, *June Medical Services v. Gee*, *Whole Women's Health v. Cole*, and *Webster v. Reproductive Health Service*. Our organization has also brought groundbreaking litigation seeking to protect access to abortion and other reproductive health care, including several cases protecting access to clinics by upholding fixed buffer zones and other reasonable limitations on protestors, seeking justice against those who commit violence at clinics, and state laws imposing burdensome regulations amounting to restricted access.

## A Trusting Patient-Provider Relationship is Essential for Public Health, and the Proposed Rule Would Further This Outcome

Increased surveillance and growing state legislation following the *Dobbs v. Jackson Women's Health Organization* decision, have raised serious concerns around requests made by law enforcement and other entities for PHI from health care providers for use against individuals who seek or obtain reproductive health care. Information about an individual's reproductive health care includes the kind of highly sensitive information that patients would be reluctant to share if they knew it could be disclosed and used against them. The pursuit and disclosure of this health information leads to medical distrust, causing patients to withhold important medical information or to discontinue necessary health care altogether, which severely undermines provision of and access to critical medical care. We commend HHS for proposing 45 CFR § 164.502(5)(iii), which prohibits the use or disclosure of PHI by covered entities for either a criminal, civil, or administrative investigation into or proceeding against any person in connection with seeking, obtaining, providing, or facilitating lawful reproductive health care or the identification of any person for the purpose of initiating such investigations or proceedings. By placing restrictions on the sharing of PHI, this rule would help improve patient trust which has eroded post-*Dobbs*.

Trust between patients and providers is essential for creating an environment where patients can be transparent with their health care providers, which will help ensure accurate diagnoses and informed treatment decisions leading to improved health care. Notably, people of color are negatively impacted as they are least likely to have equitable access to health care<sup>2</sup> and the most likely to experience poor health outcomes.<sup>3</sup> Punitive responses to substance use, pregnancy loss, self-managed abortion, or any other acts or omissions that create a perceived risk of harm during pregnancy generate negative health outcomes for pregnant individuals and their children.<sup>4</sup> In the nation with the highest maternal mortality rate in the industrialized world, with Black women three times more likely to die from pregnancy than white women,<sup>5</sup> it is critical to eradicate the pernicious practices that give pregnant patients more reason to avoid seeking necessary health care and distrust health care providers. Medical distrust in communities that have historically faced systemic discrimination in health care, including Black, Indigenous, and other communities of color, can lead to additional barriers to health care and exacerbate health care disparities in vulnerable populations.<sup>6</sup> This is also true for members of the LGBTQ+ community, and the intersectional communities therein.<sup>7</sup> Trust between patients and providers is a critical element for honest health discussions which relies heavily on privacy protections. Accordingly, Legal Momentum strongly supports policies that reduce the risk of inappropriate enforcement and thus foster trust within the patient-provider relationship.

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<sup>2</sup> Sinsi Hernández-Cancio & Venicia Gray, National Partnership for Women & Families, *Racism Hurts Moms and Babies* 1 (2021), <https://www.nationalpartnership.org/our-work/resources/health-care/racism-hurts-moms-and-babies.pdf>.

<sup>3</sup> National Partnership for Women & Families, *Maternity Care in the United States: We Can—and Must—Do Better* 8 (Feb. 2020), <https://www.nationalpartnership.org/our-work/resources/health-care/maternity-care-in-the-united.pdf>.

<sup>4</sup> American Psychological Association, *Pregnant and Postpartum Adolescent Girls and Women with Substance-Related Disorders* (March 2020), <https://www.apa.org/pi/women/resources/pregnancy-substance-disorders.pdf>.

<sup>5</sup> Latoya Hill, Samantha Artiga & Usha Ranji, Kaiser Family Foundation, *Racial Disparities in Maternal and Infant Health: Current Status and Efforts to Address Them* (2022), <https://www.kff.org/racial-equity-and-health-policy/issue-brief/racial-disparities-in-maternal-and-infant-health-current-status-and-efforts-to-address-them/>.

<sup>6</sup> Katrina Armstrong, et al., *Racial/Ethnic Differences in Physician Distrust in the United States*, 97(7) Am. J. Pub. Health 1283, 1283–1289 (2007); Liz Hamel, et al., KFF, *KFF/The Undeclared Survey on Race and Health* (Oct. 2020), <https://www.kff.org/report-section/kff-the-undeclared-survey-on-race-and-health-main-findings/>; United Nations, *The Health of Indigenous Peoples* 8–9 (June 2014), <https://www.un.org/en/ga/69/meetings/indigenous/pdf/IASG%20Thematic%20Paper%20-%20Health%20-%20rev1.pdf>.

<sup>7</sup> Shabab Ahmed Mirza & Caitlin Rooney, *Discrimination Prevents LGBTQ People From Accessing Health Care*, Ctr. for Am. Progress (Jan. 18, 2018), <https://www.americanprogress.org/article/discrimination-prevents-lgbtq-people-accessing-health-care/>; Paul Hudson & Michelle A. Williams, *People Are Much Less Likely to Trust the Medical System If They Are from an Ethnic Minority, Have Disabilities, or Identify as LGBTQ+*, According to a First-of-its-Kind Study by Sanofi, Fortune (Jan. 31, 2023, 7:30 AM), <https://fortune.com/2023/01/31/people-trust-health-medical-system-ethnic-minority-disabilities-identify-lgbtq-study-sanofi-hudson-williams/>.

## **The Proposed Rule Addresses the Urgent Need to Protect Patient Health Information in the Face of an Increasing Number of Bans on Essential Health Services, but Additional Protections Are Still Needed**

*HHS should expand protections prohibiting the disclosure of PHI in the final rule to cover all health care thereby limiting conflicts and confusion within the legal landscape*

The everchanging and conflicting legal landscape, has resulted in the criminalization of reproductive health care and created ambiguities in the law that place patients, providers, lawyers, and advocates in precarious situations, undermining their ability to aid in, receive, and provide reproductive health care. The increase in abortion bans across the country threatens patients and providers with criminal penalties for obtaining or providing essential health care. As of June 1, 2023, thirteen states have near-total abortion bans and at least six states have or are attempting to ban abortion after six weeks.<sup>8</sup> States like Texas and Idaho already criminalize individuals who aid others in accessing abortion care.<sup>9</sup> As Idaho's law specifically targets individuals who help minors seek care legally in another state, additional protections of PHI are crucial to maintaining access to care.<sup>10</sup> Moreover, the growing number of states restricting access to abortion care will further criminalize vulnerable and marginalized birthing people.<sup>11</sup> HHS should therefore expand the final rule to prohibit the disclosure of PHI for all health care thereby expanding protections and limiting conflicts and confusion within the legal landscape.

*Testing and treatment for substance use in the perinatal period must be explicitly recognized within the final rule's definition of reproductive health care*

We also urge HHS to explicitly include in its definition of "Reproductive Health Care" drug testing, drug screening, and treatment for substance use disorders throughout the perinatal period. With the rise in abortion bans, we have seen first-hand an increase in surveillance of pregnant patients, resulting in a range of negative consequences for themselves and their families. Such penalization includes the investigation, harassment, and prosecution of individuals for their pregnancies and pregnancy outcomes, whether that is miscarriage, self-managed abortion, or related to substance use during pregnancy. A prevalent way pregnant patients are being penalized and surveilled is by the practice of nonconsensual drug testing and reporting. Drug testing perinatal patients without specific, informed consent is widely opposed by leading medical organizations.<sup>12</sup> This is all the more concerning when pregnant patients are being drug tested not for any medical necessity but for the purpose of referrals to child protective services, hence resulting only in punitive outcomes. People who test positive, even for legal substances, are subsequently reported to child protective services and subjected to surveillance and the risk of family separation.<sup>13</sup> Terminating parental rights can harm children more than the supposed effects of drug use on that person's ability to parent.<sup>14</sup> Pregnant women seeking medical care

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<sup>8</sup> *State Bans on Abortion Throughout Pregnancy*, Guttmacher Inst. (June 1, 2023), <https://www.guttmacher.org/state-policy/explore/state-policies-later-abortion>.

<sup>9</sup> Kate Zernike, *Idaho Is First State to Pass Abortion Ban Based on Texas' Law*, N.Y. Times (Mar. 14, 2022), <https://www.nytimes.com/2022/03/14/us/idaho-abortion-bill-texas.html#:~:text=The%20Texas%20law%2C%20considered%20the,they%20can%20get%20an%20abortion>.

<sup>10</sup> *Id.*

<sup>11</sup> Liza Fuentes, *Inequity in US Abortion Rights and Access: The End of Roe Is Deepening Existing Divides*, Guttmacher Inst. (Jan. 17, 2023), <https://www.guttmacher.org/2023/01/inequity-us-abortion-rights-and-access-end-roe-deepening-existing-divides>.

<sup>12</sup> ACOG Committee Opinion: *Informed Consent and Shared Decision Making in Obstetrics and Gynecology*, Am. Coll. of Obstetricians & Gynecologists e34–e39 (Feb. 2021), <https://www.acog.org/-/media/project/acog/acogorg/clinical/files/committee-opinion/articles/2021/02/informed-consent-and-shared-decision-making-in-obstetrics-and-gynecology.pdf>; Aviva L. Katz & Sally A. Webb, *Informed Consent in Decision-Making in Pediatric Practice*, 138(2) *Pediatrics* e1–e4 (2016), <https://publications.aap.org/pediatrics/article/138/2/e20161485/52519/Informed-Consent-in-Decision-Making-in-Pediatric>.

<sup>13</sup> Irin Carmon, *'They Really Wanted to See My Baby Get Taken Away' A Woman is Suing a Brooklyn Hospital for Secretly Drug Testing Her During Labor*, *Intelligencer* (Mar. 21, 2023), <https://nymag.com/intelligencer/2023/03/brookdale-hospital-lawsuit-brooklyn-pregnancy-drug-testing.html>.

<sup>14</sup> Movement for Family Power, *Drug War Foster System Report* 19 (2020), <https://static1.squarespace.com/static/5be5ed0fd274cb7c8a5d0cba/t/5eead939ca509d4e36a89277/1592449422870/MFP+Drug+War+Foster+System+Report.pdf>.

should not be subject to targeted forms of surveillance that put them at unique risk of criminal liability, civil penalties, and risk of family separation.

Medical professionals have come to play a significant role in the penalization of pregnant people in a way that undermines health care. A majority of these child protective service investigations are triggered by health care providers reporting on their patients, even when they are not required to do so, with low-income women and women of color being disproportionately targeted.<sup>15</sup> These punitive measures also deprive pregnant people of fundamental constitutional rights and bodily autonomy. It is more important than ever to ensure that a patient's medical history cannot be disclosed for the purpose of such investigations and processes. The final rule should explicitly cover drug testing, drug screening, and treatment for substance use disorders in the perinatal period within its definition of reproductive health care.

*Self-managed abortions should be explicitly protected by the final rule*

We commend HHS for expanding privacy protections to cover reproductive health care that includes, but is not limited to abortion, miscarriage management, infertility treatment, contraception use, and treatment for reproductive-related conditions such as ovarian cancer. But the proposed rule can do more to protect patients' privacy interests by ensuring all PHI pertaining to reproductive health care, including self-managed abortions, are protected. Pregnant people have been arrested and prosecuted for self-managed abortions, even in states that do not prohibit or ban abortion, including self-managed abortions.<sup>16</sup> Criminalization of reproductive health care turns a safe and effective process into a dangerous system that perpetuates inequities in accessing care.<sup>17</sup> These politically motivated investigations and prosecutions aim to punish people that attempt to terminate their pregnancy—and often also end up punishing individuals who have experienced a miscarriage.<sup>18</sup> Because the law does not directly prohibit self-managed abortions, providers may be unclear as to whether the care was “lawfully” provided or obtained, thereby putting the patient at risk. Therefore, it is important that the final rule explicitly protect self-managed care.

*HHS should extend the proposed rule's protections to gender-affirming care and other forms of health care*

Legal Momentum appreciates HHS specifically asking for comment on whether to extend the proposed prohibited uses and disclosures to other forms of health care and we encourage HHS to do so. Legislative attacks on abortion care parallel those on health care for transgender people. About forty percent of states have laws restricting gender-affirming care with some having the possibility of a felony charge.<sup>19</sup> Significantly, this raises similar concerns with respect to the misuse of health data for law enforcement purposes. Twenty states have passed laws banning gender-affirming care up to age eighteen and seven additional states are considering passing similar laws.<sup>20</sup> As a result of the increase in anti-transgender legislation, eighty-six percent of transgender and non-binary young people reported a decline in mental health.<sup>21</sup> Similar to the criminalization of reproductive health care, gender-affirming care is often stigmatized and criminalized, exacerbating poor health outcomes for LGBTQ+ patients and other intersectional communities. Related 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. HHS

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<sup>15</sup> *Id.*

<sup>16</sup> Laura Huss, Farah Diaz-Tello & Goleen Samari, *If/When/How, Self-Care, Criminalized: August 2022 Preliminary Findings* 1, 3 (2022).

<sup>17</sup> *Id.* at 2.

<sup>18</sup> Robert Baldwin III, *Losing a Pregnancy Could Land You in Jail in Post-Roe America*, NPR (July 3, 2022, 5:27 AM),

<https://www.npr.org/2022/07/03/1109015302/abortion-prosecuting-pregnancy-loss>.

<sup>19</sup> Annette Choi & Will Mullery, *19 States Have Laws Restricting Gender-Affirming Care, Some with the Possibility of a Felony Charge*, CNN (June 6, 2023, 3:10 PM), <https://www.cnn.com/2023/06/06/politics/states-banned-medical-transitioning-for-transgender-youth-dg/index.html>.

<sup>20</sup> HRC Foundation, *Map: Attacks on Gender Affirming Care by State*, Human Rights Campaign (June 1, 2023),

<https://www.hrc.org/resources/attacks-on-gender-affirming-care-by-state-map>.

<sup>21</sup> Trevor News, *New Poll Emphasizes Negative Impacts of Anti-LGBTQ Policies on LGBTQ Youth*, The Trevor Project (Jan. 19, 2023),

<https://www.thetrevorproject.org/blog/new-poll-emphasizes-negative-impacts-of-anti-lgbtq-policies-on-lgbtq-youth/>.

should consider expanding the rule's protections to encompass gender-affirming care and other forms of health care.

### **Conclusion**

Legal Momentum applauds HHS for proposing this rule to strengthen privacy and protect access to reproductive health care. We appreciate your consideration of these comments and we look forward to continuing to work with HHS to promote trust between patients and providers and aim for equitable access to care. For any additional questions or guidance, please contact Kyra Batté, Staff Attorney, ([kbatte@legalmomentum.org](mailto:kbatte@legalmomentum.org)) with any questions.

Respectfully submitted,

Legal Momentum, The Women's Legal Defense and Education Fund