

June 16, 2023

Department of Health and Human Services  
Office for Civil Rights  
Attn: HIPAA and Reproductive Health Care  
Privacy NPRM  
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Submitted electronically



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**Re: Proposed Rule at 88 Fed. Reg. 23,506, RIN Number  
0945-AA20 titled “HIPAA Privacy Rule To Support  
Reproductive Health Care Privacy”**

The American Civil Liberties Union (“ACLU”) submits these comments on the proposed rule published at 88 Fed. Reg. 23,506 (proposed Apr. 17, 2023), RIN 0945-AA20, with the title “HIPAA Privacy Rule To Support Reproductive Health Care Privacy” (the “Proposed Rule” or “Rule”).

For more than 100 years, the ACLU has been our nation’s guardian of liberty, working in courts, legislatures, and communities to defend and preserve the individual rights and liberties that the Constitution and the laws of the United States guarantee to everyone in this country. With more than 1.7 million members, the ACLU is a nationwide organization that fights tirelessly in all 50 states, Puerto Rico, and Washington, D.C. for every individual’s rights.

The Proposed Rule takes important steps toward protecting health care privacy for the most vulnerable individuals and communities, guarding against the criminalization of reproductive health care. Undermining privacy protections in health care leads to a breakdown in trust between providers and patients, and to adverse health outcomes. The Health Insurance Portability and Accountability Act (“HIPAA”) Privacy Rule, as it currently stands, does not offer sufficient protections to people who access reproductive health care, or for people accessing gender-affirming healthcare, which is under similar attack. By prohibiting certain disclosures under the Privacy Rule where the purpose is to investigate or prosecute someone for accessing or providing legal health care,

the Proposed Rule advances the important goals of the Privacy Rule, to promote trust in providers and encourage individuals to access needed care.

In addition to supporting the laudable proposals put forth in the Proposed Rule, the ACLU proposes that the Department of Health and Human Services' Office for Civil Rights ("HHS" or "the Department") make the following changes to better effectuate the goals of the Privacy Rule and HIPAA itself:

- Prohibit disclosure of protected health information related to gender-affirming health care in addition to protected health information related to reproductive health care;
- Prohibit disclosure of all protected health information in response to a request for a prohibited purpose;
- Explicitly limit the definition of "public health" to exclude investigations relating to the access of lawful health care;
- Strengthen the attestation requirement, including by adding a notice provision and prohibiting derivative or secondary uses;
- Consider protections for individuals who request their own protected health information at the request of law enforcement; and
- Explicitly protect access to protected health information for defensive purposes.

In addition to these proposals, the ACLU encourages the Department to finalize the Rule expeditiously. Access to safe, legal health care is already under attack, jeopardizing the health and wellbeing of people across the country. For that same reason, the Department must also undertake a comprehensive education and outreach campaign to inform covered entities of the Rule's prohibitions. Health care providers and others covered by the Privacy Rule must understand their obligations under the Rule, and properly categorize sensitive health information in order to adequately shield it from disclosure—particularly where some providers may have access to sensitive health information related to reproductive health care or gender-affirming health care that they themselves did not provide. Accordingly, the ACLU exhorts the Department to interpret the protections in the Rule broadly, allow the Rule to go into effect quickly, and to take steps to ensure its protections are actually implemented widely.

## **I. THE DEPARTMENT SHOULD PROHIBIT THE DISCLOSURE OF HEALTH INFORMATION RELATED TO REPRODUCTIVE HEALTH CARE AND GENDER-AFFIRMING CARE.**

The Proposed Rule is a necessary step to shield individuals' access to reproductive health care, which is increasingly under threat following the Supreme Court's cataclysmic decision in *Dobbs v. Jackson Women's Health Organization*.<sup>1</sup>

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<sup>1</sup> 142 S. Ct. 2228 (2022).

Under the current Privacy Rule, a covered entity can turn over individuals’ protected health information (“PHI”) without their consent to law enforcement under a variety of circumstances.<sup>2</sup> The Department’s Proposed Rule would prohibit disclosures to law enforcement if certain criteria are met and the disclosure is “for a criminal, civil, or administrative investigation into or proceeding against any person in connection with seeking, obtaining, providing, or facilitating reproductive health care,” or to identify any person for those purposes. 88 Fed. Reg. at 23552 (to be codified at § 164.502(a)(5)(iii)(A)). The necessary criteria include that the investigation or proceeding is in connection with any person seeking, obtaining, providing, or facilitating reproductive health care 1) “*outside of the state where the investigation or proceeding is authorized and where such health care is lawful in the state in which it is provided,*” or 2) “*that is protected, required, or authorized by Federal law, regardless of the state in which such health care is provided,*” or 3) “*in the state in which the investigation or proceeding is authorized and that is permitted by the law of that state.*” 88 Fed. Reg. at 23552 (to be codified at § 164.502(a)(5)(iii)(C)) (emphasis added).

The Proposed Rule’s broad protections for reproductive health care—beyond just abortion—are necessary to accomplish the goal of the Privacy Rule, to “provide greater protections to individuals’ privacy and to engender a trusting relationship between individuals and health care providers.” 88 Fed. Reg. at 23514. Moreover, these protections should be extended to explicitly cover gender-affirming health care as well, as such care is likewise under threat in states across the country.

#### **A. The Proposed Rule’s Prohibition Against Disclosure of Reproductive Health Care PHI Is Needed to Counter Threats to Access to Care.**

The ACLU supports the Proposed Rule’s prohibition on disclosing PHI related to reproductive health care, and encourages the Department to define the term broadly. Privacy protections are absolutely needed, not only to shield what access remains of abortion care, but for all forms of reproductive health care.

Even prior to *Dobbs*, many people were not able to access abortion care due to the stigma against abortion and a coordinated effort by anti-abortion policymakers to restrict access to abortion care and coverage. Then, in *Dobbs*, the Supreme Court overturned *Roe v. Wade* and dismantled the constitutional protections provided by that decision and its progeny for nearly 50 years. In the weeks following *Dobbs*, some form of abortion ban would go into effect in over two dozen states,<sup>3</sup> and in

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<sup>2</sup> 45 C.F.R. § 164.512.

<sup>3</sup>See Michele Bratcher Goodwin, *Testimony Before the Senate Judiciary Committee On the Assault on Reproductive Rights In A Post-Dobbs America* (Apr. 6, 2023), <https://www.judiciary.senate.gov/imo/media/doc/2023-04-26%20-%20Testimony%20-%20Goodwin.pdf>.

2022 alone, over 100 bills restricting access to abortion were introduced.<sup>4</sup> The decision has allowed anti-abortion states across the country to pass or enforce laws that ban abortion and force women and others who can become pregnant into a second-class status by denying them control over their bodies and their futures.<sup>5</sup>

The devastating impact on access to abortion care post-*Dobbs* was immediately apparent. Pregnant patients have been denied critical emergency abortion care, despite serious risks to their health and lives and contrary to their doctors' medical judgment, due to restrictive abortion laws.<sup>6</sup> Sixty-six clinics in 15 different states were forced to stop offering abortions in the 100 days following *Dobbs*.<sup>7</sup> Although one in ten people already traveled out of state for abortion prior to *Dobbs*,<sup>8</sup> clinic closures and abortion bans mean that for the millions of women of reproductive age in the affected states, out-of-state travel is their only option to receive abortion care in a medical setting.<sup>9</sup> Further, people are discouraged from seeking health care, and prenatal care specifically, due to the threat of criminalization in some states.<sup>10</sup>

Forcing someone to carry a pregnancy against their will has life-altering consequences, including enduring serious health risks from continued pregnancy and childbirth, making it harder to escape poverty, derailing education, career and life plans, and making it more difficult to leave an abusive partner. The impacts of pushing abortion out of reach fall disproportionately on the same women and other people who have always faced systemic barriers to care—communities of color; people living on low-incomes; undocumented immigrant; young people; the lesbian, gay, bisexual, transgender, and queer (“LGBTQ”) community; and people with

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<sup>4</sup> See Larissa Jimenez, *60 Days After Dobbs: State Legal Developments on Abortion*, Brennan Ctr. for Just. (Aug. 24, 2022), <https://www.brennancenter.org/our-work/research-reports/60-days-after-dobbs-state-legal-developments-abortion>.

<sup>5</sup> See *An Overview of Abortion Laws*, Guttmacher Inst., <https://www.guttmacher.org/state-policy/explore/overview-abortion-laws> (last updated June 2023).

<sup>6</sup> See, e.g., *NWLC Files EMTALA and Sex Discrimination Complaints on Behalf of Mylissa Farmer*, Nat'l Women's L. Ctr. (Nov. 8, 2022), <https://nwlc.org/resource/nwlc-files-emptala-and-sex-discrimination-complaints-on-behalf-of-mylissa-farmer/>; Caroline Kitchener, *Two friends were denied care after Florida banned abortion. One almost died.*, Wash. Post (Apr. 10, 2023, 6:00 AM), <https://www.washingtonpost.com/politics/2023/04/10/pprom-florida-abortion-ban/>; Sam Karlin, *Louisiana woman who was denied an abortion for a fetus without a skull gets procedure in New York*, The Advocate (Sept. 14, 2022), [https://www.theadvocate.com/baton\\_rouge/news/louisiana-woman-who-was-denied-an-abortion-for-a-fetus-without-a-skull-gets-procedure/article\\_b23b2b48-3458-11ed-bd50-27875e9118ec.html](https://www.theadvocate.com/baton_rouge/news/louisiana-woman-who-was-denied-an-abortion-for-a-fetus-without-a-skull-gets-procedure/article_b23b2b48-3458-11ed-bd50-27875e9118ec.html).

<sup>7</sup> Marielle Kirstein et al., *100 Days Post-Roe: At Least 66 Clinics Across 15 US States Have Stopped Offering Abortion Care*, Guttmacher Inst. (Oct. 6, 2022), <https://www.guttmacher.org/2022/10/100-days-post-roe-least-66-clinics-across-15-us-states-have-stopped-offering-abortion-care>.

<sup>8</sup> Isaac Maddow-Zimet & Kathryn Kost, *Even Before Roe Was Overturned, Nearly One in 10 People Obtaining an Abortion Traveled Across State Lines for Care*, Guttmacher Inst. (Jul. 21, 2022), <https://www.guttmacher.org/article/2022/07/even-roe-was-overturned-nearly-one-10-people-obtaining-abortion-traveled-across>.

<sup>9</sup> See Kirstein et al., *supra* note 7.

<sup>10</sup> See, e.g., *US state abortion bans 'putting millions of women and girls at risk,'* United Nations (June 2, 2023), <https://news.un.org/en/story/2023/06/1137282>.

disabilities. In particular, the harms will fall hardest on Black women, who are already three times more likely than white women to die during childbirth or shortly after.<sup>11</sup> Recognizing these risks, many states have taken the initiative to pass laws protecting access to abortion,<sup>12</sup> as well as personal health data.<sup>13</sup> For example, the ACLU of Massachusetts advocated in support of a new state law that breaks down cost barriers to abortion care, protects abortion providers and helpers, and clarifies that the right to abortion is protected under law; the New York Civil Liberties Union supported a flight of state laws that provide funding for abortion care, increase access to medication abortion, and protect health care providers, among other advancements; and many other ACLU affiliates have advocated for

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<sup>11</sup> See Priya Krishnakumar & Daniel Wolfe, *How outlawing abortion could worsen America's maternal mortality crisis*, CNN (June 24, 2022), <https://www.cnn.com/2022/05/10/us/maternal-mortality-roe-wade-abortion-access/index.html>.

<sup>12</sup> See, e.g., Gabe Stern, *Nevada Republican governor approves abortion protections in cross-party move*, AP News (May 31, 2023), <https://apnews.com/article/nevada-abortion-republican-governor-joe-lombardo-83032873a48a8916b7d030191d095bc4>; Liam Reilly & Kaanita Iyer, *Maryland governor signs bills protecting abortion rights and gender-affirming care*, News Channel 3-12 (May 3, 2023, 4:27 PM), <https://keyt.com/news/2023/05/03/maryland-governor-signs-bills-protecting-abortion-rights-and-gender-affirming-care/>; Briana Bierschbach, *New laws make Minnesota a 'refuge' for abortion, gender-affirming care*, Star Tribune (Apr. 27, 2023, 6:27 PM), <https://www.startribune.com/minnesota-to-become-refuge-for-abortion-gender-affirming-care-with-new-laws/600270558/?refresh=true>; Jesse Paul, *Colorado governor signs three bills further protecting access to abortion, gender-affirming care into law. Here's what they do.*, The Colorado Sun (Apr. 14, 2023, 2:41 PM), <https://coloradosun.com/2023/04/14/jared-polis-abortion-bills-signed-2023/>; Nina Shapiro, *Amid post-Roe landscape*; Nina Shapiro, *Amid post-Roe landscape, WA lawmakers pass abortion 'shield law'*, The Seattle Times (Apr. 12, 2023, 6:00 AM), <https://www.seattletimes.com/seattle-news/politics/amid-post-roe-landscape-wa-lawmakers-pass-abortion-shield-law/>; AP, *New Mexico governor signs bill to shield abortion providers*, The Journal (last updated Apr. 7, 2023, 9:52 AM), [https://www.the-journal.com/articles/new-mexico-governor-signs-bill-to-shield-abortion-providers/?utm\\_source=substack&utm\\_medium=email](https://www.the-journal.com/articles/new-mexico-governor-signs-bill-to-shield-abortion-providers/?utm_source=substack&utm_medium=email); Candace Cheung, *Hawaii governor signs bill to strengthen abortion protections*, Courthouse News Service (Mar. 22, 2023), <https://www.courthousenews.com/hawaii-governor-signs-bill-to-strengthen-abortion-protections/>; *Press Release: Gov. Pritzker Signs Sweeping Reproductive Rights Protections Into Law* (Jan. 13, 2023), <https://www.illinois.gov/news/press-release.25906.html>; Victoria Colliver, *5 ways California is protecting abortion*, Politico (Sept. 27, 2022, 4:49 PM), <https://www.politico.com/news/2022/09/27/five-ways-california-is-protecting-abortion-00059090>; Kiely Westhoff, Samantha Beech & Shawna Mizelle, *New Jersey governor signs bills protecting out-of-state abortion seekers and reproductive health care providers*, CNN (July 1, 2022), <https://www.cnn.com/2022/07/01/politics/new-jersey-abortion-reproductive-rights-laws/index.html#:~:text=The%20bills%2C%20A3974%20and%20A3975,Jersey%20seeking%20legal%20abortion%20services>; Amy Simonson, *Delaware governor signs bill expanding abortion access and provider protection*, CNN (June 29, 2022, 9:02 PM), <https://www.cnn.com/2022/06/29/politics/delaware-governor-signs-abortion-access-law/index.html>; *Governor Hochul Signs Nation-Leading Legislative Package to Protect Abortion and Reproductive Rights for All* (June 13, 2022), <https://www.governor.ny.gov/news/governor-hochul-signs-nation-leading-legislative-package-protect-abortion-and-reproductive>; *Press Release: Watch: Governor Lamont Signs First-in-the-Nation Reproductive Rights Legislation* (May 5, 2022), <https://portal.ct.gov/Office-of-the-Governor/News/Press-Releases/2022/05-2022/Watch-Governor-Lamont-Signs-Reproductive-Rights-Legislation>.

<sup>13</sup> See, e.g., H.B. 1155, 68th Leg., 2023 Reg. Sess. (Wash. 2023) (expanding protections for private consumer health data in Washington State).

similar laws in their own states.<sup>14</sup> But particularly for people who live in restrictive states, additional protections are desperately needed.

Although state attacks on abortion are most acute, the Department is correct to extend its prohibition on disclosure to *all* reproductive health care. Even before *Dobbs*, leading medical and public health organizations were condemning the imposition of criminal sanctions or civil liability in response to individuals seeking reproductive health care as harmful to patient health and wellbeing,<sup>15</sup> because states were already criminalizing people for their pregnancy outcomes.<sup>16</sup> For example, people have been prosecuted for continuing their pregnancy while struggling with a substance use disorder, as well as for using prescribed medications and legal medical marijuana—even when there is no evidence that the drug use impacted the pregnancy outcome.<sup>17</sup> Some of these and other investigations and prosecutions have been triggered by health care providers reporting their patients to law enforcement when they were under no legal duty or responsibility to do so,<sup>18</sup> making it crucial that the Proposed Rule limits such disclosures.

Others have been prosecuted—and even sentenced to decades in prison—based on allegations that they self-managed an abortion, even in states where it is

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<sup>14</sup> See *Dozen Recommendations From Beyond Roe Agenda Signed Into Law This Week*, ACLU Mass. (July 29, 2022, 11:15 AM), <https://www.aclum.org/en/news/dozen-recommendations-beyond-roe-agenda-signed-law-week>; *Memo of Support*, N.Y.C.L.U. (Apr. 2023), [https://www.nyclu.org/sites/default/files/field\\_documents/230411-jointmemoofsupport-repro.pdf](https://www.nyclu.org/sites/default/files/field_documents/230411-jointmemoofsupport-repro.pdf).

<sup>15</sup> See generally *Medical and Public Health Group Statements Opposing Prosecution and Punishment of Pregnant Women*, Pregnancy Just. (June 2021), <https://www.pregnancyjusticeus.org/wp-content/uploads/2023/03/Medical-and-Public-Health-Group-Statements-Opposing-Prosecution-and-Punishment-of-Pregnant-Women.pdf>.

<sup>16</sup> See Sandhya Dirks, *Criminalization of pregnancy has already been happening to the poor and women of color*, NPR (Aug. 3, 2022, 10:30 AM), <https://www.npr.org/2022/08/03/1114181472/criminalization-of-pregnancy-has-already-been-happening-to-the-poor-and-women-of>.

<sup>17</sup> See, e.g., Brianna Bailey, *Oklahoma Is Prosecuting Pregnant Women for Using Medical Marijuana*, The Marshall Project (Sept. 13, 2022, 6:00 AM), <https://www.themarshallproject.org/2022/09/13/oklahoma-is-prosecuting-pregnant-women-for-using-medical-marijuana> (finding “at least 26 women charged with felony child neglect in Oklahoma since 2019 for using marijuana during their pregnancies,” when “[a]t least eight of the women had state medical marijuana licenses”); 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>; Jessica Mason Pieklo, *Murder Charges Dismissed in Mississippi Stillbirth Case*, Rewire News Group (Apr. 4, 2014, 2:43 PM), <https://rewirenewsgroup.com/2014/04/04/murder-charges-dismissed-mississippi-stillbirth-case/>.

<sup>18</sup> See, e.g., Tina Vásquez, *How misinformation about medical reporting requirements fueled Lizelle Herrera’s criminalization for abortion*, Prism (Apr. 21, 2022), <https://prismreports.org/2022/04/21/misinformation-fueled-lizelle-herrera-criminalization-abortion/>; Laura Huss, Farah Diaz-Tello, & Goleen Samari, *Self-Care, Criminalized: August 2022 Preliminary Findings*, If/When/How: Lawyering for Reproductive Just., <https://www.ifwhenhow.org/resources/self-care-criminalized-preliminary-findings/> (“39% of the cases [criminalizing people for self-managing abortions] were reported to law enforcement by healthcare providers”); Radio Iowa Contributor, Radio Iowa Contributor, *Burlington woman will not be charged with feticide*, Radio Iowa (Feb. 10, 2010), <https://www.radioiowa.com/2010/02/10/burlington-woman-will-not-be-charged-with-feticide/>.

not a crime.<sup>19</sup> To be clear, except under rare circumstances, it is not a crime to receive abortion care or self-manage one’s own abortion.<sup>20</sup> And there are no laws that would require a report to law enforcement by a health care provider concerning a self-managed abortion.<sup>21</sup> Accordingly, the Department should make clear when finalizing this rule, and through additional guidance, that covered entities are prohibited in the overwhelming majority of situations from reporting a patient seeking care following a self-managed abortion to law enforcement under the Privacy Rule.

Further, opponents of reproductive freedom have already demonstrated that they will not be content to stop at banning abortion—they have also set their sights on individual’s access to contraception. Already, there have been numerous lawsuits seeking to make it harder for people to access contraception, such as by demanding a right to decline to provide insurance coverage for contraception, as required by the Affordable Care Act, or by prohibiting minors from accessing free contraception without their parents’ permission.<sup>22</sup> Policymakers are working to undermine access to contraception, including by conflating birth control and abortion, and by hiding restrictions on contraception in those provisions meant to restrict abortion.<sup>23</sup> And though *Griswold v. Connecticut* held that there is constitutional protection for the right to access contraception,<sup>24</sup> there are increasing calls for courts to find that this case too was “demonstrably erroneous,” and should be overruled like *Roe v. Wade*.<sup>25</sup>

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<sup>19</sup> See Huss et al., *supra* note 18 (identifying “61 cases of people who were criminally investigated or arrested for allegedly ending their own pregnancy or helping someone else do so” from 2000 to 2020); Associated Press, *Indiana Court Tosses Purvi Patel’s 2015 Feticide Conviction*, NBC News (July 22, 2016, 12:31 PM), <https://www.nbcnews.com/news/asian-america/indiana-court-tosses-purvi-patel-s-2015-feticide-conviction-n615026>.

<sup>20</sup> 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, *preliminary injunction granted by Planned Parenthood South Atlantic v. South Carolina*, Ct. Common Pleas for the 5th Jud. Cir., C/A No.: 2023-CP-40-002745 (May 26, 2023).

<sup>21</sup> See *Patient Confidentiality and Self-Managed Abortion: A Guide to Protecting Your Patients and Yourself*, If/When/How: Lawyering for Reproductive Justice (2020), <https://providecare.org/wp-content/uploads/2022/08/PatientConfidentialityAndSMA.pdf>.

<sup>22</sup> See, e.g., *Little Sisters of the Poor Saints Peter & Paul Home v. Pennsylvania*, 140 S. Ct. 2367 (2020); *Burwell v. Hobby Lobby Stores, Inc.*, 573 U.S. 682, 689–91 (2014); *Deanda v. Becerra*, No. 2:20-CV-092-Z, 2022 WL 17572093, at \*17 (N.D. Tex. Dec. 8, 2022), *judgment entered*, No. 2:20-CV-092-Z, 2022 WL 17843038 (N.D. Tex. Dec. 20, 2022).

<sup>23</sup> See *Don’t Be Fooled: Birth Control is Already at Risk*, Nat’l Women’s L. Ctr. (June 17, 2022), <https://nwlc.org/resource/dont-be-fooled-birth-control-is-already-at-risk/>.

<sup>24</sup> *Griswold v. Connecticut*, 381 U.S. 479 (1965).

<sup>25</sup> *Dobbs v. Jackson Women’s Health Org.*, 142 S. Ct. 2228, 2301 (2022) (“[I]n future cases, we should reconsider all of this Court’s substantive due process precedents, including *Griswold*, *Lawrence*, and *Obergefell*.”) (Thomas, J., concurring); see also Melissa Brown, *Sen. Marsha Blackburn criticizes 1965 Supreme Court ruling on birth control access*, The Tennessean (last updated Mar. 23, 2022, 11:41 AM), <https://www.tennessean.com/story/news/politics/2022/03/21/marsha-blackburn-criticizes-1965-supreme-court->

In sum, individuals are already at risk of being subject to legal actions by law enforcement and other government officials when accessing many forms of reproductive health care beyond abortions.

But even if the Proposed Rule were only intended to protect against threats to abortion in particular, it would be necessary to prohibit disclosures related to reproductive health care generally. If records related to abortion care are withheld, but other records are not, law enforcement could still use those records to draw inferences as to whether people had accessed abortion care. For example, health information related to someone’s menstrual cycle, pregnancy status, or use of emergency contraception, among many other data points related to someone’s reproductive health, could be used to establish that someone sought to end their pregnancy. Protecting reproductive health care broadly is thus necessary to ensure that the purpose of the Proposed Rule is not undermined.

### **B. The Proposed Rule’s Explicit Prohibition on Disclosures Should Be Extended to Gender-Affirming Care.**

The ACLU also urges the Department to add explicit protections for PHI related to gender-affirming health care to the final rule. On March 2, 2022, in response to attacks on gender-affirming care for minors in Texas and an escalation of rhetoric against transgender people nationwide, HHS issued a Notice and Guidance on Gender Affirming Care, Civil Rights and Patient Privacy, which included a summary of the existing privacy protections under HIPAA.<sup>26</sup> Because the state landscape on access to treatment for gender dysphoria has changed in significant ways over the past year, the existing balance under HIPAA does not adequately protect the privacy of this sensitive medical information. We ask HHS to respond now to the crisis the transgender community is currently facing.

As HHS has already recognized, gender-affirming health care is well-recognized medical care. The Office of Population Affairs at HHS has defined gender-affirming care as “an array of services that may include medical, surgical, mental health, and non-medical services for transgender and nonbinary people. For transgender and nonbinary children and adolescents, early gender-affirming care is crucial to overall health and well-being as it allows the child or adolescent to focus on social transitions and can increase their confidence while

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ruling-birth-control/7120236001/ (“U.S. Sen. Marsha Blackburn this weekend called a landmark 1965 Supreme Court ruling legalizing access to contraception ‘constitutionally unsound’”); Steve Benen, *Asked about contraception case, GOP candidates give the wrong answer*, MSNBC (Feb. 21, 2022, 9:36 AM), <https://www.msnbc.com/rachel-maddow-show/maddowblog/asked-contraception-case-gop-candidates-give-wrong-answer-rcna17053>.

<sup>26</sup> U.S. Dep’t of Health and Hum. Servs., *HHS Notice and Guidance on Gender Affirming Care, Civil Rights and Patient Privacy* (Mar. 2, 2022), <https://www.hhs.gov/sites/default/files/hhs-ocr-notice-and-guidance-gender-affirming-care.pdf>.



navigating the health care system.”<sup>27</sup> Specific medical interventions appropriate to treat gender dysphoria may include puberty-delaying medication for transgender youth, hormone treatment, and surgery when medically indicated. Every major medical organization in the United States, including the American Academy of Pediatrics and the American Medical Association, recognizes that these treatments are medically necessary for some transgender young people and adults to treat gender dysphoria, and that they are safe and effective treatments.<sup>28</sup>

All of the important public health interests supporting expanded protections for PHI related to reproductive health supports adding more explicit privacy protections for PHI related to gender-affirming health care alongside the current proposed protections for general reproductive health care information.

Since 2021, twenty states have passed laws or enacted policies that ban some or all gender-affirming medical care for transgender youth.<sup>29</sup> In 2023 alone, one hundred and thirty state bills were introduced that target this care.<sup>30</sup> Some of these newly enacted laws are criminal bans, and some are civil bans that come with a range of penalties for medical providers.<sup>31</sup> Even before bans on care were enacted, Attorneys General in Texas and Missouri had issued opinions attempting to restrict access to this health care, and in Texas last year, the Department of Child and Family Services began opening child abuse investigations to remove children from their homes simply because their parents sought best practice medical care for them, causing extraordinary harm to transgender youth and their families.<sup>32</sup> At this time, these attacks in Arkansas, Alabama, Florida, and Texas have been enjoined by courts, and many other bans are currently being challenged.

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<sup>27</sup> OASH, *Gender Affirming Care and Young People*, HHS Off. of Pop. Affs. <https://opa.hhs.gov/sites/default/files/2022-03/gender-affirming-care-young-people-march-2022.pdf>.

<sup>28</sup> See, e.g., Jason Rafferty et al., *Ensuring Comprehensive Care and Support for Transgender and Gender-Diverse Children and Adolescents*, *Am. Acad. of Pediatricians* (Oct. 1, 2018), <https://publications.aap.org/pediatrics/article/142/4/e20182162/37381/Ensuring-Comprehensive-Care-and-Support-for?autologincheck=redirected>; James L. Madara, *Letter to National Governors Association*, *Am. Med. Assoc.* (Apr. 26, 2021), available at <https://searchlf.ama-assn.org/letter/documentDownload?uri=%2Funstructured%2Fbinary%2Fletter%2FLETTERS%2F2021-4-26-Bill-McBride-opposing-anti-trans-bills-Final.pdf>.

<sup>29</sup> See Kiara Alfonseca, *Map: Where gender-affirming care is being targeted in the US*, *ABC News* (May 22, 2023, 11:43 AM), <https://abcnews.go.com/US/map-gender-affirming-care-targeted-us/story?id=97443087>.

<sup>30</sup> See *Mapping Attacks on LGBTQ Rights in U.S. State Legislatures*, *ACLU* (last updated June 9, 2023), <https://www.aclu.org/legislative-attacks-on-lgbtq-rights?redirect=legislation-affecting-lgbtq-rights-across-country&impact=health>.

<sup>31</sup> Criminal bans have been enacted in Alabama, Idaho, North Dakota, and Oklahoma. See S.B. 184, 2022 Leg. Reg. Sess. (Ala. 2022); H.B. 71, 67th Leg., Reg. Sess. (Idaho 2023); H.B. 1254, 68th Leg. Assemb. (N.D. 2023); S.B. 613, 1st Sess., 59th Leg. (Okla. 2023).

<sup>32</sup> See, e.g., Madeleine Carlisle, *‘I’m Just Waiting for Someone to Knock on the Door.’ Parents of Trans Kids in Texas Fear Family Protective Services Will Target Them*, *Time* (May 19, 2022, 6:24 PM), <https://time.com/6178947/trans-kids-texas-families-fear-child-abuse-investigations/>.

In addition, attacks on gender-affirming care for adults are escalating. In Florida, the ban on health care for minors that passed this year also included extreme restrictions on adults accessing care.<sup>33</sup> Other states have imposed restrictions on access to gender-affirming care by denying insurance coverage to state employees, prohibiting the state Medicaid program from covering this health care, and prohibiting care for people who are incarcerated.<sup>34</sup>

As a result of these attacks on necessary medical care, many transgender people and their families are being forced to seek care outside of their home states. Some are considering moving to less hostile states, while many others are accessing care in a different state where it remains lawful and returning to their home state.<sup>35</sup> Ensuring that this PHI is not able to be used against families in criminal investigations or in spurious child abuse investigations, or against medical providers who are offering care that is lawful in the state in which they practice, is critically important to ensuring this care remains accessible and confidential.<sup>36</sup>

The need to protect this information is urgent. In Texas, the state Attorney General is now investigating a hospital regarding its policies for treating transgender youth,<sup>37</sup> and in Missouri the Attorney General is seeking medical records for lawful medical care for transgender patients, prompting lawsuits from Children's Mercy Hospital and Planned Parenthood of the St. Louis Region and Southwest Missouri<sup>38</sup> And Florida's Governor DeSantis's continued attacks on the LGBTQ community include a recent request to all state universities to provide him with information about the number and ages of students receiving gender-affirming health care.<sup>39</sup>

If transgender people and their families fear that information about health care that they are lawfully able to access will be used against them by law enforcement or in similar contexts, that would dramatically decrease trust and worsen medical outcomes. The risk that such information may be used against

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<sup>33</sup> See S.B. 254, 2023 Leg. Sess. (Fla. 2023).

<sup>34</sup> See, e.g., Azeen Ghorayshi, *Many States Are Trying to Restrict Gender Treatments for Adults, Too*, N.Y. Times (Apr. 22, 2023), <https://www.nytimes.com/2023/04/22/health/transgender-adults-treatment-bans.html>.

<sup>35</sup> See, e.g., Madeleine Carlisle, *As Texas Targets Trans Youth, a Family Leaves in Search of a Better Future*, Time (July 14, 2022, 8:41 AM), <https://time.com/6196617/trans-kids-texas-leave/>.

<sup>36</sup> See, e.g., Society for Adolescent Health & Medicine, *Statement on the Politicization of Gender-Affirming Care and Threats of Violence Against Clinicians* (Apr. 20, 2023), <https://www.adolescenthealth.org/SAHM-News/SAHM-Statement-about-the-Politicization-of-Gender.aspx>.

<sup>37</sup> See Jim Vertuno, *Texas investigates hospital over care for transgender minors*, AP News (May 5, 2023), <https://apnews.com/article/texas-transgender-hospital-investigation-greg-abbott-dce466dcaa7be541c009a2fdc0b4a286>.

<sup>38</sup> See *Hospital sues Missouri's top prosecutor over trans care data*, Assoc. Press (Apr. 15, 2023), <https://apnews.com/article/transgender-care-missouri-attorney-general-hospital-lawsuit-217e78b46cfd50432c97e3cc759f9717>.

<sup>39</sup> See Associated Press, *DeSantis seeks transgender university students' health care information*, NBC News (Jan. 19 2023, 3:27 PM), <https://www.nbcnews.com/nbc-out/out-politics-and-policy/desantis-seeks-transgender-university-students-health-care-information-rcna66495>.

medical providers may also deter providers in states where it is lawful from continuing to offer this necessary health care to people from states that have banned the care, or even at all. For all these reasons, we urge the Department to amend the final rule to explicitly protect PHI related to gender-affirming health care, in addition to PHI related to reproductive health care.

### **C. Disclosure of All PHI Should be Prohibited in the Covered Circumstances.**

The Proposed Rule must clarify the scope of the prohibited disclosure under the Privacy Rule, to better protect individuals' sensitive PHI. As currently written, the Proposed Rule prohibits disclosure of "protected health information potentially related to reproductive health care" if it is for a prohibited purpose. 88 Fed. Reg. at 23553 (to be codified at § 164.509(a)). The Department should clarify that a covered entity cannot disclose *any* PHI, whether it is potentially related to reproductive health care or not, if the underlying purpose of the request is an investigation or proceeding regarding reproductive or gender-affirming health care. A separate provision of the Proposed Rule seems to take this approach, by stating that a covered entity "may not use or disclose protected health information," if it is for a prohibited purpose. 88 Fed. Reg. at 23552 (to be codified at § 164.502(a)(5)(iii)(A)). That broader approach should be adopted in full in the final rule.

Prohibiting the disclosure of all PHI if it is for a prohibited purpose will make the Rule easier to enforce and more effective. The Department already recognizes the challenges of segregating health information related to reproductive health care, particularly as "many types of PHI may not initially appear to be related to an individual's reproductive health but may in fact reveal information about an individual's reproductive health or reproductive health care." 88 Fed. Reg. at 23521. For example, weight gain, nausea and vomiting, high blood pressure, and glucose found in urine may all be indications of particular pregnancy conditions.<sup>40</sup> Indeed, providers have been working with their electronic health records vendors to develop the capacity to segregate records and suppress particular pieces of information, but have met reticence from the companies who do not wish to create this capability, and those who have been able to negotiate some limited segregation abilities have found that they are constantly discovering new fields that need to be suppressed to properly protect their patients. Additionally, if individuals' health records are turned over with notable gaps, these records could still inform law enforcement that the patient likely received reproductive health care.

Accordingly, if an individual's PHI is requested for a prohibited purpose, the requestor should not be entitled to any of their PHI, as the disclosure of any medical

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<sup>40</sup> Ctr. for Disease Control & Prevention, *Pregnancy Complications*, U.S. Dep't of Health & Hum. Servs., [https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-complications.html?CDC\\_AA\\_refVal=https%3A%2F%2Fwww.cdc.gov%2Freproductivehealth%2Fmaternalinfanthealth%2Fpregcomplications.htm](https://www.cdc.gov/reproductivehealth/maternalinfanthealth/pregnancy-complications.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Freproductivehealth%2Fmaternalinfanthealth%2Fpregcomplications.htm) (last visited June 14, 2023).

information could create harmful inferences about the reproductive or gender-affirming care they had received. Extending proposed Section 164.509(a) to all PHI would have an additional benefit: it would harmonize possible tensions between Section 164.509(a) and proposed Section 164.502(a)(5)(iii)(A). At the very least, the Department should prohibit the disclosure of the entire record of *any visit* at which *any care* related to reproductive or gender-affirming health care was provided, when sought for a prohibited purpose.

#### **D. The Proposed Rule is Needed to Protect Marginalized Communities.**

The need for the Proposed Rule to apply broadly is particularly acute for our country's most marginalized communities, which are more often criminally investigated and prosecuted for seeking access to reproductive care. Black and Brown low-income women are most likely to be targeted, investigated, and prosecuted for their reproductive health choices.<sup>41</sup> This trend is not new but stems from an historical tradition of controlling and regulating the bodies of Black women as a form of oppression.<sup>42</sup> Low-income people are also typically without access to legal counsel until formal charges are filed, at which time disclosure of their reproductive records has likely already occurred.<sup>43</sup> The Proposed Rule would create reasonable protections for the privacy of those individuals most at risk of being unfairly targeted, investigated, and prosecuted for accessing lawful medical care.

## **II. THE PROPOSED RULE'S DEFINITIONS ARE NECESSARY TO BETTER PROTECT HEALTH CARE ACCESS.**

### **A. The Proposed Rule's Definition of "Person" Is Necessary.**

The ACLU supports the Proposed Rule's clarification that a "person" for purposes of the rule is limited to a "natural person (meaning a human being who is born alive)." 88 Fed. Reg. at 23552 (to be codified at § 160.103). As the preamble explains, a "person" for purposes of the Proposed Rule "does not include a fertilized egg, embryo, or fetus." 88 Fed. Reg. at 23523. This definition is needed to prevent law enforcement entities from attempting to avoid the Proposed Rule's disclosure prohibitions by, for example, claiming to have a request that is actually about a

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<sup>41</sup> Meghan Boone, *Reversing the Criminalization of Reproductive Health Care Access*, 48 Am. J.L. Med. 200, 201 (2022).

<sup>42</sup> Monica Siwiec, *Note: Policing Pregnancy Loss: Misuse of Abuse of a Corpse Laws*, 4 Cardozo Int'l & Comp. L. Rev. 1007, 1022 (2021) (citing Dorothy Roberts, *Killing the Black Body: Race Reproduction, and the Meaning of Liberty* 6 (1998)).

<sup>43</sup> The right to counsel attaches only once formal judicial proceedings have begun, "whether by way of formal charge, preliminary hearing, indictment, information, or arraignment." *Rothgery v. Gillespie Cty.*, 554 U.S. 191, 198 (2008) (quotation and citation omitted). A person has no right to counsel during a police investigation prior to the "onset of formal prosecutorial proceedings." *Kirby v. Illinois*, 406 U.S. 682, 690 (1972).

fertilized egg, embryo, or fetus, and not about the person seeking reproductive health care.

This concern is not speculative. Numerous states have already codified laws that extend “personhood” rights to fetuses, embryos, and fertilized eggs. For example, although Arizona’s personhood law has been enjoined,<sup>44</sup> personhood laws are in effect in Alabama, Missouri, and Georgia.<sup>45</sup> Additionally, in 2021 and 2022, legislatures in Iowa, Indiana, Montana, Ohio, Oklahoma, South Carolina, Texas, Vermont, and West Virginia introduced similar bills.<sup>46</sup> Not only could such laws potentially be used as back-door abortion bans, personhood laws could be used for state surveillance and regulation of the conduct of pregnant people. Accordingly, HHS is correct to include a definition of “person” in the Rule, and the specificity of its definition is appropriate.

### **B. The Proposed Rule’s Explicit Limit on the Definition of “Public Health” to Exclude Investigations Relating to the Access of Lawful Reproductive or Gender-Affirming Health Care Is Needed.**

The ACLU applauds HHS for recognizing the need to limit when a regulated entity may disclose PHI for “public health” surveillance, investigation, or intervention. We support the proposed definition of “public health” to limit its scope and exclude from its definition any criminal, civil, or administrative investigation into or proceeding against any person in connection with seeking, obtaining, providing, or facilitating reproductive care, or to identify any person for the purpose of initiating such an investigation or proceeding. While the proposed definition is consistent with a general understanding of what constitutes public health surveillance, investigation, or intervention, the law enforcement community often interprets its duty to protect public safety as part of a broader goal of maintaining and promoting public health.<sup>47</sup> This broader interpretation of public health investigations to include criminal investigations and prosecutions, if not explicitly rejected, would allow unintended disclosures of otherwise protected sensitive health care PHI.

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<sup>44</sup> *Isaacson v. Brnovich*, 610 F. Supp. 3d 1243, 1257 (D. Ariz. 2022).

<sup>45</sup> Ala. Const. art. I, § 36.06(a) (“[I]t is the public policy of this state to recognize and support the sanctity of unborn life and the rights of unborn children, including the right to life”); Mo. Rev. Stat. § 188.026.2(1)–(2) (finding that “life of each human being begins at conception and that unborn children have protectable interests in life, health, and well-being”); *SisterSong Women of Color Reprod. Just. Collective v. Governor of Georgia*, 40 F.4th 1320, 1326–28 (11th Cir. 2022) (vacating injunction against Georgia’s personhood law).

<sup>46</sup> See *State Legislation Tracker: Major Developments in Sexual & Reproductive Health*, Guttmacher Inst., <https://www.guttmacher.org/state-legislation-tracker> (last updated May 15, 2023) (see data entitled “Bans Abortion by Establishing Fetal Personhood”).

<sup>47</sup> See, e.g., *Policing and Public Health*, Int’l Ass’n Chiefs of Police, <https://www.theiacp.org/publichealth> (discussing policing strategies to address public health issues such as “violence, mental illness, homelessness, and substance use disorders and overdoses”) (last visited June 14, 2023).

Excluding criminal investigations and prosecutions from the definition of public health investigations is consistent with research demonstrating that criminalization of reproductive and other health care undermines—rather than promotes—public health. As discussed above, people have already been subject to prosecution and other punitive measures for their pregnancy outcomes, and states have passed criminal bans on gender-affirming care for transgender youth. This criminalization of health care chills individuals’ willingness to access necessary care, even where legal, out of fear that doing so may expose them to potential criminal liability.<sup>48</sup> For example, laws criminalizing fetal assault instill fear of interrogation, arrest, and prosecution of pregnant people who are themselves victims of abuse, creating barriers to access medical services.<sup>49</sup> The criminalization of continuing a pregnancy despite a substance use disorder disincentivizes a pregnant person from being honest with their medical care provider about their drug use and obtaining appropriate care and support, or even from obtaining prenatal care altogether, increasing the risk of complications.<sup>50</sup> The criminalization of certain sexual conduct chills people from obtaining care for sexually transmitted infections, undermining the medical community’s ability to track and control preventable and treatable disease.<sup>51</sup> The harmful consequences of these criminal policies demonstrate the disconnect between policing and public health, and thus support HHS’s proposed definition.

Even beyond the reproductive and gender-affirming health care contexts, the criminal legal system at large produces negative public health consequences. America’s Drug War and the criminalization of substance use discourages people from seeking medical care for their substance use disorders and increases overdose risks.<sup>52</sup> Police practices often target people with mental health disabilities, resulting

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<sup>48</sup>See *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*, Am. Coll. Obstetricians & Gynecologists (Dec. 2020), <https://www.acog.org/clinical-information/policy-and-position-statements/statements-of-policy/2020/opposition-criminalization-of-individuals-pregnancy-and-postpartum-period> (“Policies and practices that criminalize individuals during pregnancy and the postpartum period create fear of punishment that compromises [the patient-practitioner] relationship and prevents many pregnant people from seeking vital health services.”).

<sup>49</sup> *Id.* (“Any statute or legal measure that utilizes the criminal legal system as a way to control or manage behaviors during pregnancy is counterproductive to the overarching goal of improving maternal and neonatal outcomes.”).

<sup>50</sup> Rebecca Stone, *Pregnant Women and Substance Use: Fear, Stigma, and Barriers to Care*, 3 Health & Just. at 13 (Feb. 12, 2015) (discussing studies demonstrating that “punitive policies have indeed had some chilling effect on women’s help-seeking behavior by discouraging women from accessing prenatal care or leading them to skip appointments, and by motivating women who did attend appointments to withhold medically relevant information”).

<sup>51</sup> Ctrs. for Disease Control & Prevention, *HIV Criminalization Legal and Policy Assessment Tool*, 6–7 (2022), <https://www.cdc.gov/hiv/pdf/policies/law/hiv-criminalization-legal-and-policy-assessment-tool.pdf> (explaining that laws “that criminalize conduct by people with HIV, may provide little to no public health benefits or even actively cause harm” including “delaying or avoiding HIV testing and treatment as well as exposing individuals who have been prosecuted under HIV criminalization laws to additional health risk factors associated with the criminal legal system”).

<sup>52</sup> Human Rights Watch & American Civil Liberties Union, *Every 25 Seconds: The Human Toll of*

in their incarceration rather than treatment.<sup>53</sup> Mass incarceration leads not only to poorer health outcomes for those who are incarcerated,<sup>54</sup> but negatively impacts the broader community and especially the children of incarcerated parents.<sup>55</sup> Prisons and jails themselves serve as vectors of disease, contributing to greater community spread of infection.<sup>56</sup> These examples further support HHS's proposed definition of public health to exclude criminal prosecutions and investigations.

### **III. THE DEPARTMENT SHOULD STRENGTHEN THE ATTESTATION REQUIREMENT AND CLARIFY PERMITTED PURPOSES.**

The proposed attestation requirement (to be codified at 45 C.F.R. § 164.509) is an important mechanism for enforcing compliance with the prohibitions on disclosure in the proposed amendments to Section 164.502, and should be retained in the final rule. However, without further enhancement, the attestation requirement is unlikely to adequately protect against abusive requests for and prohibited disclosure of PHI. As outlined below, there are several changes the Department can make to the final rule that would offer more opportunities to protect against improper disclosures. At the same time, the Department must explore ways to protect individuals who request their own PHI on behalf of law enforcement, as a means to circumvent the Proposed Rule's protections, as well as to explicitly protect access to PHI for the purpose of allowing a criminally or civilly accused person to mount their legal defense.

#### **A. The Department Must Strengthen the Attestation Requirement.**

The ACLU proposes the following improvements to the attestation requirement to better ensure that PHI related to sensitive health care is not improperly released, and is protected from prohibited uses following release.

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*Criminalizing Drug Use in the United States* 165 (Oct. 2016), <https://www.aclu.org/report/every-25-seconds-human-toll-criminalizing-drug-use-united-states> (“Criminalization drives drug use underground; it discourages access to emergency medicine, overdose prevention services, and risk-reducing practices such as syringe exchanges; and, by incarcerating people who use drugs—too often without proper medical attention—it causes deterioration of physical and mental health and increases significantly the risk of overdose upon release.”). Congress has recognized the immense public health benefits of protecting substance abuse treatment records from law enforcement access in 42 U.S.C. § 290dd-2.

<sup>53</sup> *Criminalization of People with Mental Illness*, Nat'l All. on Mental Illness, <https://www.nami.org/Advocacy/Policy-Priorities/Stopping-Harmful-Practices/Criminalization-of-People-with-Mental-Illness>.

<sup>54</sup> *Incarceration and Health: A Family Medicine Perspective (Position Paper)*, Am. Acad. of Fam. Physicians, (July 2021), <https://www.aafp.org/about/policies/all/incarceration.html>.

<sup>55</sup> Melissa Noel & Cynthia Najowski, *When parents are incarcerated, their children are punished, too*, Am. Psychol. Ass'n (Sept. 1, 2019), <https://www.apa.org/monitor/2019/09/jn>.

<sup>56</sup> See, e.g., Kristin Samuelson, *High incarceration rates fuel COVID-19 spread and undermine U.S. public safety*, Northwestern Now (Sept. 2, 2021), <https://news.northwestern.edu/stories/2021/september/incarceration-covid-19-spread-public-safety/>.

1. *Require notice to the individual.*

The current Privacy Rule recognizes the importance of providing individuals with robust information about use and disclosure of their PHI.<sup>57</sup> In particular, the Privacy Rule already recognizes the importance of pre-disclosure notice to the individual when their PHI is subject to a request pursuant to a subpoena or other legal process.<sup>58</sup> Such notice provides individuals with an opportunity to seek to quash abusive or illegal requests, and to take other steps to preserve the privacy of their PHI. However, existing notice requirements do not reach all of the situations where health care information may be requested in violation of the Proposed Rule—for example, pursuant to a law enforcement request under Section 164.512(f).

A notice requirement should be added to Section 164.509. Providing notice to individuals when a covered entity receives an attestation will serve two purposes. First, it will provide a failsafe when the covered entity does not have information to evaluate the accuracy of an attestation that the use or disclosure is not for a prohibited purpose. *See* 88 Fed. Reg. at 23553 (to be codified at § 164.509(c)(1)(iv)). An individual may have access to information about the purpose for which their PHI has been requested, and may be able to alert the covered entity when an attestation misrepresents that purpose. Second, notice will enable the individual to take steps, such as retaining an attorney or filing a motion to quash, to protect their PHI if they believe the request is improper or illegal.

Notice could be provided in one of two ways. One way would be for the requesting entity to provide notice to the individual and include proof of such notice with the attestation. Notice should clearly explain the information that is contained in the attestation, as well as include information about how the individual can contact the covered entity to raise objections. As with the notice provision in 45 C.F.R. § 164.512(e)(iii), the covered entity should not comply with the request that is the subject of the attestation until sufficient time has passed for the individual to object. Alternately, the covered entity itself can provide notice, including a clear explanation of the information contained in the attestation and an explanation of how the individual may object to the covered entity's compliance with the request. In situations where the request seeks PHI of a "class of individuals," *see* 88 Fed. Reg. at 23553 (to be codified at § 164.509(c)(1)(i)(B)), only the covered entity will have contact information for the affected individuals, and so the covered entity will be in the best position to provide notice. In that and other situations where providing notice will pose a cost for the covered entity, the Proposed Rule should require that the requesting entity reimburse the covered entity for the reasonable cost of providing notice.

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<sup>57</sup> *See, e.g.*, 45 C.F.R. § 164.528 (providing right to an accounting of disclosures of protected health information).

<sup>58</sup> *Id.* § 164.512(e)(ii)–(iii).



2. *Prohibit derivative or secondary prohibited uses of protected health care information.*

The Proposed Rule bars disclosure when it is “*primarily* for the purpose of investigating or imposing liability on any person for the mere act of seeking, obtaining, providing, or facilitating reproductive health care.” 88 Fed. Reg. at 23553 (to be codified at § 164.502(a)(5)(iii)(D)) (emphasis added). This fails to protect against disclosure of protected information when the asserted primary purpose is permissible, but when the requestor may later use or disclose the information for the purpose of investigating or imposing liability on a person for seeking, obtaining, providing, or facilitating protected care. Section 164.509(c)(1)(iv) of the Proposed Rule should be amended to require the requesting entity to attest both that “the use or disclosure is not for a purpose prohibited under § 164.509(a)(5)(iii),” and that the requestor will not *later* use or disclose PHI for a prohibited purpose, even if such later use or disclosure is not contemplated at the time of the initial request.

Additionally, where possible, the requesting entity should be required to enter into a protective order barring it from using or disclosing the PHI for a prohibited purpose. The current Privacy Rule requires protective orders in the context of disclosures in the course of judicial or administrative proceedings.<sup>59</sup> Protective orders should also be required for law enforcement requests,<sup>60</sup> including those pursuant to *ex parte* warrants or court orders, where the law enforcement agency can be required to include use and disclosure restrictions in the warrant or court order itself. Grand jury subpoenas and administrative subpoenas and summonses should also be accompanied by a signed guarantee that the requesting entity will not use or disclose the PHI for a prohibited purpose, and a binding commitment to convert that guarantee into a court-issued protective order in the event that the recipient of the subpoena or summons declines to comply and the requestor seeks an order to compel. Any such order to compel should be required to contain or attach a binding protective order.

3. *Liability for misrepresentations in attestations.*

The explanatory text accompanying the Proposed Rule states that “a requester who knowingly falsifies an attestation . . . to obtain (or cause to be disclosed) an individual’s IIHI would be in violation of HIPAA and could be subject to criminal penalties as outlined in the statute.” 88 Fed. Reg. at 23536 (citing 42 U.S.C. § 1320d-6). However, there may be uncertainty as to whether HIPAA’s criminal penalties apply only to HIPAA covered entities (*i.e.*, health plans, health care clearinghouses and health care providers), or whether they can also impose liability on a requestor, such as a civil litigant, law enforcement agency or state

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<sup>59</sup> See *id.* § 164.512(e)(1)(v).

<sup>60</sup> See *id.* § 164.512(f).

agency, that is not itself a covered entity.<sup>61</sup> HHS should provide greater explanation of how current law may protect against false statements in attestations, and should investigate whether there are additional mechanisms that would incentivize truthful and accurate attestations under the Proposed Rule.

### **B. The Department Should Consider Protections for Individuals Who Request Their Own PHI on Behalf of Law Enforcement.**

The ACLU shares HHS's concern that law enforcement may be able to circumvent the attestation requirement by having individuals request that their own PHI be sent directly to law enforcement. *See* 88 Fed. Reg. 23533. The ACLU agrees with HHS's determination that an individual should be able to control access to their own medical records. But those who are the subject of a criminal investigation or prosecution may be placed in situations where a request from law enforcement to access their health records does not result in a truly voluntary consent to disclosure. Requests from law enforcement are often seen as having the force of law and are therefore frequently acquiesced to even when the person would prefer to refuse.<sup>62</sup> People subject to a criminal investigation are further placed in coercive environments where that person's free will can be easily undermined.<sup>63</sup> Police also use deceptive tactics to pressure individuals to waive their rights in order to obtain evidence that can later be used against them.<sup>64</sup> There is no reason to believe that law enforcement would not use these same techniques to obtain authorization from individuals to disclose their own PHI.

In light of these concerns, we encourage HHS to study ways to better protect individuals from being pressured or coerced into requesting their own reproductive or gender-affirming health care records as an end run around the attestation requirement. In particular, HHS should consider whether reproductive or gender-affirming health care PHI disclosures should only be sent directly to the requester,

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<sup>61</sup> 42 U.S.C. § 1320d-6 (part of the Administrative Simplification provision of HIPAA) has been interpreted to impose liability only on HIPAA covered entities. *See* Memorandum Op. for the Gen. Counsel of the Dep't of Health & Hum. Servs. & Senior Counsel to the Deputy Att'y Gen., from Steven G. Bradbury, Principal Deputy Assistant Atty. Gen., Off. of Legal Counsel Re: Scope of Criminal Enforcement Under 42 U.S.C. § 1320d-6 (June 1, 2005), <https://www.justice.gov/d9/olc/opinions/attachments/2015/05/28/op-olc-v029-p0076.pdf>. Congress amended § 1320d-6 in 2009, with language that appears to impose criminal liability more broadly. Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009, Pub. L. No. 111-5, § 13409, 123 Stat. 271, 271 (2009). However, at least one court has continued to interpret § 1320d-6 to apply only to covered entities even since that amendment. *See Wells v. Enter. Leasing Co. of Norfolk/Richmond, LLC*, 500 F. Supp. 3d 478, 484 (E.D. Va. 2020).

<sup>62</sup> Janice Nadler, *No Need to Shout: Bus Sweeps and the Psychology of Coercion*, 2002 Sup. Ct. Rev. 153, 173–86 (2002) (discussing social science illustrating how people feel compelled to comply with requests from authority figures).

<sup>63</sup> *See Miranda v. Arizona*, 384 U.S. 436, 467 (1966) (recognizing inherently coercive atmosphere of custodial interrogation); *but see United States v. Watson*, 423 U.S. 411, 424 (1976) (holding that consent provided by defendant was voluntary even though defendant was in custody and was not advised that he could withhold consent).

<sup>64</sup> Rebecca Strauss, *We Can Do This the Easy Way or the Hard Way: The Use of Deceit to Induct Consent Searches*, 100 Mich. L. Rev. 868, 882–86 (2002) (discussing use of deception to obtain consent).

and whether the disclosures must be accompanied by a notice of the person's rights under the Privacy Rule.

### **C. The Department Should Explicitly Protect Access to PHI for Defensive Purposes.**

The ACLU agrees with HHS that the Proposed Rule should not prohibit a regulated entity from disclosing PHI for a defensive purpose. The ACLU recommends, however, that the proposed Section 164.512(c)(3) more explicitly state that its rule of construction permits such use and disclosure. As HHS acknowledges, the Proposed Rule “[w]hen read in isolation” would “seemingly prevent” entities from disclosing for the purpose of defending themselves or others related to a criminal prosecution. 88 Fed. Reg. at 23532. Given the importance these records may have to a person's ability to defend oneself from liability, the ACLU suggests that HHS consider more explicit language to state that disclosure is appropriate for defensive purposes.

The ability to effectively defend oneself in a criminal prosecution can hinge on a person's ability to investigate, obtain, and present evidence relevant to their own defense.<sup>65</sup> As a result, access to reproductive or gender-affirming health care records may be essential to defending against charges that a person obtained or provided unlawful care. For example, where law enforcement alleges that a doctor has engaged in unlawful reproductive medical care, that doctor may need to access the patient's reproductive health care PHI to demonstrate otherwise. But because the doctor would be alleging that the reproductive health care was lawfully provided, the Proposed Rule could be read to prohibit such disclosure. Given the significant constitutional rights at stake, the ACLU suggests that the Rule of Construction at proposed Section 164.512(c)(3) more explicitly state that the Rule of Applicability at proposed Section 164.502(a)(5)(iii)(C) does not prohibit disclosure and use of such records when the requestor seeks them for a defensive purpose.

### **IV. STATES LACK A SUBSTANTIAL INTEREST IN OBTAINING PHI RELATED TO LAWFULLY PROVIDED CARE.**

The ACLU agrees with HHS that states do not have a “substantial interest” in seeking disclosure of PHI where the care being provided is legal, either under federal law or the law of the state where the care was provided. 88 Fed. Reg. at 23516. Given the increase in individuals seeking reproductive and gender-affirming health care outside of their state, it is worth emphasizing that states lack a substantial interest in requesting PHI about care provided in another state, where the health care provided was legal in that state. This is not an idle concern, as

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<sup>65</sup> See *Washington v. Texas*, 388 U.S. 14, 18–19 (1967) (holding that defendants have right to compulsory process to present witnesses); *Strickland v. Washington*, 466 U.S. 668, 680 (1984) (holding that effective assistance of counsel includes a duty to investigate).

states are already working to extend their abortion bans extraterritorially.<sup>66</sup> For example, the ACLU has filed a lawsuit to stop the Idaho Attorney General from enforcing a legal opinion in which he claims that Idaho law bars Idaho-based health care providers from referring patients out of state for abortion care, and implies that Idaho’s abortion ban applies beyond its borders.<sup>67</sup> Several states have already considered laws that would prevent people from traveling out of state to access abortion care,<sup>68</sup> and some of the bans on gender-affirming care include language that could be interpreted to reach referrals to access care out of state.<sup>69</sup> However, based on fundamental tenets of due process and the constitutional right to travel, states lack a substantial interest in investigating or prosecuting activity that was legal in the state where it occurred.

### A. Due Process Clause.

First, it would violate the Due Process Clause of the U.S. Constitution for states to punish conduct that occurs wholly outside their borders.<sup>70</sup> “A basic principle of federalism is that each State may make its own reasoned judgment about what conduct is permitted or proscribed within its borders, and each State alone can determine what measure of punishment, if any, to impose on a defendant who acts within its jurisdiction.”<sup>71</sup> Accordingly, it is long-established that a state cannot prosecute a person “for doing within the territorial limits of [another state] an act which that [separate] state had specially authorized him to do.”<sup>72</sup> Acts that are “done within the territorial limits of [one state], under authority and license from that state . . . cannot be prosecuted and punished by . . . [a different] state.”<sup>73</sup> The Supreme Court has reiterated this principle time and time again, including in the context of abortion-related activity.<sup>74</sup>

The constitutional prohibition against punishing out-of-state conduct that is legal where it occurs is based on both structural and fairness concerns. Structurally,

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<sup>66</sup> Caroline Kitchener & Devlin Barrett, *Antiabortion lawmakers want to block patients from crossing state lines*, Wash. Post (June 29, 2022, 8:30 AM), <https://www.washingtonpost.com/politics/2022/06/29/abortion-state-lines/>.

<sup>67</sup> *Planned Parenthood Great Northwest, Hawai’i, Indiana, Kentucky v. Labrador*, American Civil Liberties Union (last updated Apr. 6, 2023), <https://www.aclu.org/cases/planned-parenthood-great-northwest-hawaii-indiana-kentucky-v-labrador>.

<sup>68</sup> Stella Tallmon, *The Post-Dobbs Legality of Out-of-State Abortion Travel Bans*, Columbia Undergraduate L. Rev. (Jan. 6, 2023), <https://www.culawreview.org/journal/the-post-dobbs-legality-of-out-of-state-abortion-travel-bans>.

<sup>69</sup> See Mississippi H.B. 1125 (2023) (prohibiting providers from “aiding and abetting” any minor from accessing gender-affirming care); Indiana S.B. 480 (2023) (same); Iowa S.F. 538 (2023) (same).

<sup>70</sup> *BMW of N. Am., Inc. v. Gore*, 517 U.S. 559, 573 n.19 (1996).

<sup>71</sup> *State Farm Mut. Auto. Ins. Co. v. Campbell*, 538 U.S. 408, 422 (2003).

<sup>72</sup> *Nielsen v. Oregon*, 212 U.S. 315, 321 (1909).

<sup>73</sup> *Id.*

<sup>74</sup> *Bigelow v. Virginia*, 421 U.S. 809, 824 (1975) (holding Virginia could not criminalize publication of advertisement concerning availability of abortion services in New York that were, at the time of publication and prosecution, illegal in Virginia but legal in New York).

state laws simply “have no force of themselves beyond the jurisdiction of the State” under the principles of federalism and comity.<sup>75</sup> And from a fairness perspective, “[t]o punish a person because he has done what the law plainly allows him to do is a due process violation of the most basic sort.”<sup>76</sup>

Additionally, these principles apply whether states wish to extend their abortion bans to apply to out-of-state health care providers, who are just “doing an act which [their] state . . . authorized and gave [them] . . . license[s] to do,”<sup>77</sup> or to citizens of their state who travel to another state to receive an abortion.<sup>78</sup> When a patient or a health care provider travels outside of a state to receive or perform an abortion that occurs in a state where such conduct is legal, that conduct is beyond the state’s jurisdiction to regulate. Any in-state effects of that conduct are equally irrelevant to the due process problems created by out-of-state enforcement.<sup>79</sup>

## **B. Right to Travel.**

Second, it would violate the right to travel for states to investigate or prosecute their citizens for leaving their state to access reproductive or gender-affirming health care. The Supreme Court has recognized that a constitutional “right to travel” . . . protects the right of a citizen of one State to enter and to leave another State, the right to be treated as a welcome visitor rather than an unfriendly alien when temporarily present in the second State, and, for those travelers who elect to become permanent residents, the right to be treated like other citizens of that State.”<sup>80</sup>

This right to travel shields individuals who leave their home state to access health care that is barred at home but permitted in another state, as well as the providers who offer that care in the state where it is permitted. As Justice Kavanaugh explained in his concurrence in *Dobbs*, “based on the constitutional right to interstate travel,” a state could not “bar a resident of that State from traveling to another State to obtain an abortion.”<sup>81</sup>

Accordingly, the constitutional rights to travel and due process confirm that states do not have a substantial interest in obtaining PHI based on care that was provided outside of their borders—particularly where such care is legal in the state where it was provided.

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<sup>75</sup> *BMW*, 517 U.S. at 571 n.16; *State Farm*, 538 U.S. at 422 (explaining that it is a “basic principle of federalism” that each state holds sole authority for “what conduct is permitted or proscribed within its borders,” including the right to “determine what measure of punishment” is appropriate for that conduct).

<sup>76</sup> *BMW*, 517 U.S. at 573 n.19 (quotation marks and citation omitted).

<sup>77</sup> *Nielsen*, 212 U.S. at 321.

<sup>78</sup> *See Bigelow*, 421 U.S. at 824 (states do not acquire power over the affairs of other states simply because its citizens travel there).

<sup>79</sup> *State Farm*, 538 U.S. at 421.

<sup>80</sup> *Saenz v. Roe*, 526 U.S. 489, 500 (1999).

<sup>81</sup> *Dobbs*, 142 S. Ct. at 2309 (Kavanaugh, J., concurring).

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We greatly appreciate the efforts by HHS to strengthen privacy protections for sensitive health information related to reproductive health care. Once put in place through a final rule, these protections will positively impact the health and well-being of millions of people in the United States. We look forward to our continued work with HHS to implement our proposed changes and ensure swift implementation of the final rule. If you have any questions, please feel free to reach out to Liz Jarit at [ljarit@aclu.org](mailto:ljarit@aclu.org).

Respectfully,



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