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Office for Civil Rights
Department of Health and Human Services
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, S.W.
Washington, DC 20201

Attn: HIPAA and Reproductive Health Care Privacy NPRM

Re: Comments on RIN 0945-AA20

The Lawyers' Committee for Civil Rights Under Law ("Lawyers' Committee") appreciates the opportunity to comment on the Notice of Proposed Rulemaking ("NPRM")¹ issued by the Office for Civil Rights of the Department of Health and Human Services ("HHS") regarding protections for reproductive health privacy under the Standards for Privacy of Individually Identifiable Health Information ("Privacy Rule") implementing the Health Insurance Portability and Accountability Act ("HIPAA").

We support the proposed amendments to the Privacy Rule (the "Proposed Rule") as a critical means to increase trust in the health care system and thereby facilitate access to reproductive health care, especially for Black communities and other communities of color. By prohibiting covered entities' disclosure of protected health information ("PHI") for purposes of a criminal, civil, or administrative investigation or proceeding in connection with seeking, obtaining, providing or facilitating reproductive health care, or for identifying a person for purposes of initiating any such investigation or proceeding, the Proposed Rule will help mitigate medical mistrust in Black communities and other communities of color, and reduce racial disparities that result from the increased criminalization of reproductive health care. The proposed prohibition would apply only with respect to health care that (1) is provided outside of the state where the investigation or proceeding is authorized and where such health care is lawfully provided; (2) is protected, required, or authorized by Federal law, regardless of the state in which such health care is provided; or (3) is provided in the state in which the investigation or proceeding is authorized and that is permitted by the law of that state,² thereby affecting only circumstances in which the care provided is lawful. Although we urge HHS to consider a rule that provides broader protections for people in circumstances where reproductive health care was not obtained "lawfully," we applaud HHS's efforts thus far.

¹ HIPAA Privacy Rule to Support Reproductive Health Care Privacy, 88 Fed. Reg. 23,506 (proposed Apr. 17, 2023) (to be codified at 45 C.F.R. pt. 160, 164) [hereinafter, "NPRM"].

² NPRM at 23,539.

The Lawyers' Committee is a nonpartisan, nonprofit racial justice organization formed in 1963 at the request of President John F. Kennedy to enlist the private bar's leadership and resources in combating racial discrimination and the resulting inequality of opportunity—work that continues to be vital today. The Lawyers' Committee uses legal advocacy to achieve racial justice, fighting inside and outside the courts to ensure that Black people and other people of color have voice, opportunity, and power to make the promises of our democracy real. For nearly 60 years, the Lawyers' Committee has been at the forefront of many of the most significant cases involving racial discrimination and civil rights. Restrictions on reproductive health care prevent individuals from freely exercising their rights to bodily autonomy and self-determination, and, thus, impair their civil rights, and the Lawyers' Committee therefore strongly opposes such restrictions.

The Biden Administration has expressed a desire to pursue systemic policies that “provide comprehensive, holistic maternal health care that is free from bias and discrimination.”³ In 2021, President Joseph R. Biden first explicitly recognized the disparate burden on birthing Black people by recognizing April 11th to 17th as Black Maternal Health Week.⁴ The Proposed Rule is a key step toward eliminating this burden.

HHS has accurately identified in the NPRM the critical importance of PHI privacy protections to individuals' willingness to seek reproductive health care and to have access to such care. As the NPRM reminds us, “the primary goal of the Privacy Rule was to provide greater protections to individuals' privacy and to engender a trusting relationship between individuals and health care providers,”⁵ and thus to encourage individuals to seek the health care they need. This was also the primary goal of HHS in drafting its regulations protecting the confidentiality of substance abuse treatment information.⁶ As HHS recognized in that context, heightened privacy requirements are essential to prevent the fear of stigma, investigation, and prosecution from discouraging individuals from seeking health care treatment.⁷ “Experience shows that medical mistrust—especially in vulnerable communities that have been negatively affected by historical and current health care

³ Presidential Action, *A Proclamation on Black Maternal Health Week, 2021*, WHITE HOUSE (April 13, 2021), <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/04/13/a-proclamation-on-black-maternalhealth-week-2021/>.

⁴ Presidential Action, *A Proclamation on Black Maternal Health Week, 2021*, WHITE HOUSE (April 13, 2021), <https://www.whitehouse.gov/briefing-room/presidential-actions/2021/04/13/a-proclamation-on-black-maternalhealth-week-2021/>. Black Maternal Health Week is a campaign led and founded by the advocacy group Black Mamas Matter Alliance. *Black Mamas Matter Alliance*, (last visited June 13, 2023), <https://blackmasmatter.org/about/>. Biden most recently recognized Black Maternal Health Week in April, 2023. Presidential Action, *A Proclamation on Black Maternal Health Week, 2021*, WHITE HOUSE (APRIL 10, 2023), <https://www.whitehouse.gov/briefing-room/presidential-actions/2023/04/10/a-proclamation-on-black-maternal-health-week-2023/>.

⁵ NPRM at 23,514.

⁶ 42 C.F.R. pt. 2 (2020).

⁷ Confidentiality of Substance Use Disorder, 87 Fed. Reg. 74216, 74221-23 (2022) (codified in 42 C.F.R. pt. 2).

disparities—can create damaging and chilling effects on individuals' willingness to seek appropriate and lawful care for medical conditions that can worsen without treatment.”⁸

The post-*Dobbs* legal environment has dangerously exacerbated the bases for such mistrust, undermining the ability for Black communities and other historically marginalized populations to seek safe and equitable reproductive health care without facing the threat of criminalization. The Department’s proposed modifications to the Privacy Rule are critical to prevent such mistrust from discouraging individuals to seek reproductive health care post-*Dobbs*. The Lawyers’ Committee is particularly concerned about the impact of *Dobbs* on Black communities and other communities of color, many of whom already have a deep-seated distrust of medical institutions, as the medical establishment has historically treated Black people and other people of color less favorably, and more freely provided their information to investigators.⁹ The Proposed Rule’s prohibition on sharing PHI related to legal reproductive decisions is key to reducing such distrust, and potentially reducing the disproportionately high rate of Black maternal mortality and morbidity.¹⁰

In our more detailed comments below, we urge HHS to:

- Move forward with the proposed modifications to the Privacy Rule to protect the civil rights of members of Black communities and other communities of color, as well as members of the LGBTQI+ community;
- Retain the Proposed Rule’s bar on an individual providing an authorization for a covered entity to use and/or disclose the individual’s PHI in circumstances where the Proposed Rule would otherwise prohibit such uses or disclosures; and
- Clarify that the Privacy Rule does not mandate retention of PHI for six years or any other period of time and that, under the “minimum necessary” standard, covered entities and business associates have an obligation to retain the minimum amount of PHI needed to perform their health care-related functions.

⁸ NPRM at 23,508.

⁹ E.g., Martha Hostetter & Sarah Klein, Understanding and Ameliorating Medical Mistrust Among Black Americans, THE COMMONWEALTH FUND (Jan. 14, 2021), <https://www.commonwealthfund.org/publications/newsletter-article/2021/jan/medical-mistrust-among-black-americans> (explaining the American medical establishment’s long history of mistreating Black Americans, including in the context of reproductive healthcare).

¹⁰ Joli Hunt, *Maternal Mortality Among Black Women in the United States*, BALLARD BRIEF (Jul. 2021), <https://ballardbrief.byu.edu/issue-briefs/maternal-mortality-among-black-women-in-the-united-states>.

I. The Proposed Rule is Needed to Mitigate the Disproportionate Health-Related Harms Caused by the Criminalization of Lawful Reproductive Health Care for Black People and Other People of Color, as Well as the LGBTQI+ Community.

In Section VI of the NPRM, HHS seeks feedback on whether people in marginalized communities “are more likely to be subjects of investigations into or proceedings...in connection...with lawful reproductive health care,” how marginalized people are disproportionately affected by privacy concerns, and whether they “are less likely to have access to legal representation.”¹¹ And, in Section IV.B.4 of the NPRM, HHS seeks feedback on whether “health care providers’ concerns about potential criminal, civil, or administrative proceedings against them or their patients” bear negative effects.¹² We address the former question immediately below and the latter in Part I(C) of this letter.

People of color are more likely to experience criminalization and other investigatory intervention in connection with their reproductive decision-making. Their data privacy concerns are particularly pertinent given this disparity. Further, these individuals are statistically less likely to have access to adequate legal representation.¹³ This is particularly true for Black women, who are more likely to face discrimination in the legal system—including by prosecutors, who are overwhelmingly white—¹⁴ and who are more likely to live in poverty, and thus unable to afford representation than other racial groups.¹⁵

¹¹ NPRM at 23,551.

¹² NPRM at 23,534.

¹³ See, Rebecca Buckwalter-Poza, *Making Justice Equal*, CENTER FOR AMERICAN PROGRESS (Dec. 8, 2016), <https://justicegap.lsc.gov/resource/section-4-seeking-and-receiving-legal-help/> (explaining that people of color are more likely to live in poverty and more likely to need legal assistance). See also, Mary C. Slosar, *The Justice Gap: The Unmet Civil Legal Needs of Low-income Americans*, LEGAL SERVICES CORPORATION (2022), <https://justicegap.lsc.gov/resource/section-4-seeking-and-receiving-legal-help/> (asserting that that “low-income Americans did not receive any legal help or enough help for 92% of the[ir] problems.”) .

¹⁴ A study conducted in 2015 showed that 95 percent of prosecutors in the United States were white and only 1 percent are women of color. See *Justice For All: Who Prosecutes in America?* Reflective Democracy Campaign (July 2015), <https://wholeads.us/research/justice-for-all-report-elected-prosecutors/>.

¹⁵ Black and Indigenous people are significantly more likely to live in poverty than other groups in the United States (21.7 and 25.9 percent, respectively, compared to poverty rates of 9.5 percent for white Americans). See *Poverty Rate by Race/Ethnicity*, KFF (2021), <https://www.kff.org/other/state-indicator/poverty-rate-by-raceethnicity/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>.

A. Racial Disparities in Reproductive Health Care Contribute to Worse Health Outcomes, Higher Rates of Criminalization, and Medical Mistrust Among Black Women and Other People of Color as well as LGBTQI+ Individuals.

The relationship between the medical community and Black patients has been shaped by decades of abuse, neglect, and mistreatment of such patients, especially in the field of gynecology. The development of modern gynecology involved inhumane and violent experimentation on enslaved Black women.¹⁶ Still today, as studies and surveys of Black patients demonstrate, implicit bias and explicit racism by health care professionals worsen treatment outcomes for Black birthing people.¹⁷ Approximately 74 percent of Black people who give birth in the United States do so at hospitals that predominantly serve Black communities.¹⁸ Patients who receive care at Black-serving hospitals are more likely to have negative health outcomes than patients who receive care at hospitals that primarily serve white people.¹⁹

These disparities occur in a context where care overall is sorely deficient. Although the United States spends more on health care than any other comparable country,²⁰ health outcomes for pregnant people in America are far worse than for people who give birth in any other developed country.²¹ In one year, the CDC estimated that 50,000 women experienced a health event qualifying as a severe morbidity.²² The effects of maternal

¹⁶ DEIRDRE COOPER OWENS, *MEDICAL BONDAGE* 78 (2017).

¹⁷ Stephanie Teleki, *Challenging Providers to Look Within Themselves: A New Tool to Reduce Bias in Maternity Care*, HEALTH AFFAIRS (July 6, 2021), <https://www.healthaffairs.org/doi/10.1377/forefront.20210630.980773/>. See also Jamila K. Taylor, *Structural Racism and Maternal Health Among Black Women*, 48 J.L. MED. & ETHICS 506, 511 (2020).

¹⁸ Elizabeth A. Howell et al., *Black-White Differences in Severe Maternal Morbidity and Site of Care*, 214 AM. J. OBSTETRICS & GYNECOLOGY at 2 (2016).

¹⁹ Samsiya Ona et al., *Services and Payer Mix of Black-Serving Hospitals and Related Severe Maternal Morbidity*, 224 AM. J. OBSTETRICS & GYNECOLOGY 605e.1, 605e.1 (2021). See Proclamation No. 10365, 87 Fed. Reg. 22095 (Apr. 8, 2022).

²⁰ See Emma Wagner et al., *How Does Health Spending in the U.S. Compare to Other Countries?*, KFF (Jan. 21, 2022), <https://www.healthsystemtracker.org/chart-collection/health-spending-u-s-compare-countries-2/>.

²¹ Roosa Tikkanen et al., *Maternal Mortality and Maternity Care in the United States Compared to 10 Other Developed Countries*, THE COMMONWEALTH FUND (Nov. 18, 2020), <https://www.commonwealthfund.org/publications/issue-briefs/2020/nov/maternal-mortality-maternity-care-uscompared-10-countries>.

²² *Id.* “Severe maternal morbidity” refers to the unanticipated outcomes and health problems that result from pregnancy and result in short- or long-term consequences to the pregnant person’s health. Eugene Declercq & Laurie Zephyrin, *Maternal Mortality in the United States; A Primer*, THE COMMONWEALTH FUND (Oct. 28, 2021), <https://www.commonwealthfund.org/publications/issue-briefs/2021/oct/severe-maternal-morbidity-united-states-primer>. “Maternal mortality” describes circumstances in which a pregnant person passed away as a result of the complications they experienced during pregnancy, at birth,

morbidity on a pregnant person are wide-ranging and include heart disease, diabetes, depression, hysterectomy, and infection from cesarean section.²³

The maternal health crisis in the United States is especially acute for historically marginalized communities and, in particular, for Black and Indigenous people who give birth.²⁴ While outcomes for white people who give birth are still worse in the United States in comparison to other countries, Black people face significantly higher rates of complication during pregnancy. In 2020, approximately 19 out of 100,000 pregnant white people died in connection with birth or pregnancy.²⁵ But in the same year, approximately 55 out of 100,000 pregnant Black people died in connection with their pregnancies.²⁶ The Centers for Disease Control and Prevention estimates that, over time, Black people who give birth are three to four times more likely to die than their white counterparts due to complications related to their pregnancy.²⁷ In addition, the cause of death for Black patients is different from what drives death for white patients. A report in 2018 showed that while mental health problems are the leading cause of death for non-Hispanic white women who give birth, preeclampsia and eclampsia are the leading causes of death for Black women.²⁸

These statistics suggest the need to strongly encourage Black women and other people of color to obtain quality reproductive health care. However, these same individuals face significantly higher rates of criminalization when seeking reproductive health care, leading many to forego seeking the care they need.²⁹ Black women face the highest rates of criminalization related to pregnancy, with one study finding that 52 percent of pregnant

or post-partum as long as the death was caused or aggravated by the pregnancy or management of pregnancy. *Id.*

²³ *Id.*

²⁴ Emily E. Petersen et. al, *Vital Signs: Pregnancy-Related Deaths, United States, 2011–2015, and Strategies for Prevention*, 13 States, 2013–2017, 68 MORB. & MORTAL WKLY. REP. 423, 425 (2019), <https://www.cdc.gov/mmwr/volumes/68/wr/pdfs/mm6818e1-H.pdf>.

²⁵ The Associated Press, *Pregnancy-Related Deaths for U.S. Mothers Rose In Pandemic's First Year, Report Shows*, NBC NEWS (Feb. 23, 2022, 7:47 AM) <https://www.nbcnews.com/news/us-news/pregnancy-related-deaths-us-mothers-rose-pandemics-first-year-report-s-rcna17313>.

²⁶ Donna L. Hoyert, *Maternal Mortality Rates in the United States, 2020*, NCHS HEALTH E-STATS, at 1 (2022), <https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/E-stat-Maternal-Mortality-Rates-2022.pdf>.

²⁷ *Why Black Women Face a High Risk of Pregnancy Complications*, HARV. SCH. OF PUB. HEALTH (2019), <https://www.hsph.harvard.edu/news/hsph-in-the-news/black-women-pregnancy-complications/>.

²⁸ *Building U.S. Capacity to Review and Prevent Maternal Deaths: Report from Nine Maternal Mortality Review Committees*, CTNS. DISEASE CONTROL & PREVENTION FOUND at 6 (2018), <https://www.cdcfoundation.org/sites/default/files/files/ReportfromNineMMRCs.pdf>

²⁹ *Human Rights Crisis: Abortion in the United State After Dobbs*, HUMAN RIGHTS WATCH (Apr. 18, 2023), <https://www.hrw.org/news/2023/04/18/human-rights-crisis-abortion-united-states-after-dobbs>.

individuals who faced arrest or forced intervention were Black.³⁰ And there are significant racial and economic disparities in the enforcement of pregnancy-related crimes.³¹ Higher rates of maternal mortality and morbidity, as well as higher rates of miscarriage and need for abortion services, among Black women put them at higher risk of criminalization.³²

Visits to medical providers in connection with reproductive care should foster trust and healing—not serve as an entry point to the criminal legal system.³³ Fear of criminalization and unwanted state intervention decreases autonomy for pregnant people and also decreases their willingness to seek needed medical care.³⁴ One woman in California, for example, was recently arrested in connection with the accidental death of her newborn during home birth. Prosecutors alleged that her decision to deliver at home was neglect constituting murder and child endangerment, but she explained that she opted for home birth after medical providers reported her two previous healthy births to the California Child Welfare Services in 2012 and 2019.³⁵ Fear of losing this child, she said, led her to reject the medical establishment.

In addition, many persons who identify as LGBTQI+ have a deep mistrust surrounding the medical community, particularly in light of the recent enactment of laws banning access to or criminalizing gender-affirming care for transgender youth.³⁶ Overall, LGBTQI+ individuals face higher rates of arrest and incarceration than those in other groups,³⁷ are more likely to face discrimination and mistreatment when seeking health care,

³⁰ Lynn M. Paltrow, *Arrests of and Forced Interventions on Pregnant Women in the United States*, 38 J. OF HEALTH POL., POL'Y, & L.299, 311 (2013).

³¹ Lynn M. Paltrow, *Arrests of and Forced Interventions on Pregnant Women in the United States*, 38 J. OF HEALTH POL., POL'Y, & L.299, 311 (2013).

³² Cecilia Lenzen, *Facing Higher Teen Pregnancy and Maternal Mortality Rates, Black Women Will Largely Bear the Brunt of Abortion Limits*, THE TEXAS TRIBUNE (Jun. 30, 2022), <https://www.texastribune.org/2022/06/30/texas-abortion-black-women/>; Sudesha Mukherjee, et al. *Risk of Miscarriage Among Black Women and White Women in a US Prospective Cohort Study*, 177 A.J.E. 1273-1277 (2013); Robert Baldwin III, *Losing a Pregnancy Could Land You in Jail in post-Roe America*, NPR (Jul. 3, 2022), <https://www.npr.org/2022/07/03/1109015302/abortion-prosecuting-pregnancy-loss>.

³³ *Id.*

³⁴ *Opposition to Criminalization of Individuals During Pregnancy and the Postpartum Period*, AM. COL. 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%20period>.

³⁵ Sam Levin, *She Lost Her Child In a Home Birth. Prosecutors Charged Her With Murder*, THE GUARDIAN (Apr. 3, 2023 6:00 PM), <https://www.theguardian.com/us-news/2023/apr/03/pregnancy-birth-murder-charge-kelsey-carpenter-san-diego>.

³⁶ See Annette Choie & Will Mullery, *19 states have laws restricting gender-affirming care, some with the possibility of a felony charge*, CNN (June 2023), <https://www.cnn.com/2023/06/06/politics/states-banned-medical-transitioning-for-transgender-youth-dg/index.html>.

³⁷ Alexi Jones, *Visualizing the Unequal Treatment of LGBTQ People in the Criminal Justice System*, PRISON POLICY INITIATIVE (Mar 2, 2021), <https://www.prisonpolicy.org/blog/2021/03/02/lgbtq/>.

and frequently avoid medical care due to discrimination.³⁸ LGBTQI+ people of color face some of the highest rates of mistreatment in health care settings.³⁹ And, Black transgender and gender non-conforming people face staggeringly high rates of hate-motivated violence, with one study finding that Black transgender women accounted for 60 percent of fatal violence against transgender and gender non-conforming people between 2013 and 2020.⁴⁰

These circumstances create a strong deterrent among LGBTQI+ people of color to seek reproductive health care. “Individuals from both BIPOC communities and LGBTQI+ communities face neglect from medical professionals and systems” and are likely to avoid seeking medical care because of fear of discrimination and the potential repercussions that may come along with it,⁴¹ as HHS notes in the NPRM.⁴² In light of the decision in *Dobbs*, the disparate impact on communities of color also extends to LGBTQI+ communities and heightens mistrust in a difficult medical landscape. Given the unique barriers facing the LGBTQI+ community, HHS should consider ways in which to the current rulemaking could address the need for increased privacy protection for PHI regarding gender-affirming health care.

The deterrents to obtaining care discussed above are likely to become even more severe as many states restrict access to reproductive health care. One study showed that nationwide abortion bans may increase maternal mortality for Black people by up to 33 percent.⁴³ Early and consistent medical intervention is key to decreasing the number of preventable adverse pregnancy-related health outcomes among pregnant people.⁴⁴ For such intervention to occur, however, pregnant people must be able to trust that their

³⁸ Caroline Medina & Lindsay Mahowald, *Discrimination and Barriers to Well-Being: The State of the LGBTQI+ Community in 2022*, CENTER FOR AMERICAN PROGRESS (Jan. 12, 2023), <https://www.americanprogress.org/article/discrimination-and-barriers-to-well-being-the-state-of-the-lgbtqi-community-in-2022/>.

³⁹ *Id.*

⁴⁰ “*I Just Try to Make It Home Safe*”: *Violence and the Human Rights of Transgender People in the United States*, HUMAN RIGHTS WATCH (Nov. 18, 2021), <https://www.hrw.org/report/2021/11/18/i-just-try-make-it-home-safe/violence-and-human-rights-transgender-people-united>.

⁴¹ Cirrus Jahangiri, *What the Supreme Court’s Dobbs Decision Means for LGBTQ+ Rights*, LEGAL AID AT WORK (Aug. 2022), <https://legalaidatwork.org/what-the-supreme-courts-dobbs-decision-means-for-lgbtq-rights/> (36% of transgender people who have been pregnant considered trying to end pregnancy by themselves ‘without clinical supervision’; almost 1/5 went through with an attempt. Factors that led transgender people to end their pregnancies themselves include fear of intimate partner violence, and discrimination based on provider opinions on abortion or the patient’s gender identity.”).

⁴² NPRM at 23,521 n.180 (citing *Issue Brief: Health Insurance Coverage and Access to Care for LGBTQ+ Individuals: Current Trends and Key Challenges*, U.S. Dep’t of Health and Human Servs., Assistant Sec’y for Policy & Evaluation, Office of Health Policy (June 2021), p. 9).

⁴³ Jean Stevenson, *The Pregnancy-Related Mortality Impact of a Total Abortion Ban in the United States: A Research Note on Increased Deaths Due to Remaining Pregnant*, 58 DEMOGRAPHY 2019, 2023 (2021).

⁴⁴ *Preventing Pregnancy-Related Deaths*, CENTER FOR DISEASE CONTROL AND PREVENTION, (Apr. 26, 2023) <https://www.cdc.gov/reproductivehealth/maternal-mortality/preventing-pregnancy-related-deaths.html>.

medical providers will not subject them to surveillance for their pregnancy outcomes—whether by receiving intentional abortion care or experiencing unwanted pregnancy loss. For better health outcomes, especially for Black communities, individuals must be able to rely on providers.

The Proposed Rule has the potential to establish greater trust between patients and medical providers. By limiting opportunities for law enforcement and other entities to access sensitive information on reproductive decision-making, Black people and other historically marginalized people, as well as others who pursue lawful reproductive care, may be more likely to seek healthcare, which may in turn work to lower the current extraordinary rates of maternal mortality and morbidity.

B. The Proposed Rule Is Needed to Prevent Unwarranted Disclosures of PHI in the Post-*Dobbs* Legal Environment.

Even prior to the Supreme Court’s decision in *Dobbs* and the influx of state abortion bans criminalizing reproductive care, upwards of 1,300 people in the United States had been arrested for actions related to pregnancy outcomes between 2006 and 2020.⁴⁵ Since the *Dobbs* ruling, the risks of reproductive health care-related liability have increased exponentially. Under Texas S.B. 8, for example, private citizens may bring civil actions against anyone who knowingly “aids or abets” an abortion.⁴⁶ In the process of a civil suit, courts could issue orders to obtain abortion-related PHI.⁴⁷ And although there currently is no legislation criminalizing abortion seekers, South Carolina and Nevada have criminalized self-managed abortion,⁴⁸ and Oklahoma has also introduced a bill that would eliminate language that protects pregnant people from prosecution under the abortion ban.⁴⁹

Further, many states have some form of fetal protection law, which some prosecutors have used to charge individuals who have experienced pregnancy loss. By 2016, prosecutors in 45 states used these laws to prosecute actions including for *legal* prescription drug use, alleging that they brought about pregnancy loss.⁵⁰ Some prosecutors

⁴⁵ NATIONAL ADVOCATES FOR PREGNANT WOMEN, *Fact Sheet: Arrests and Other Deprivations of Liberty of Pregnant Women, 1973-2020*, <https://www.nationaladvocatesforpregnantwomen.org/wp-content/uploads/2021/09/Arrests-of-Pregnant-Women-1973-2020-Fact-Sheet.pdf>.

⁴⁶ 2021 Tex. SB 8. Sec. 171.208(2).

⁴⁷ Meredith Deliso, *How the Texas abortion law may actually be enforced*, ABC NEWS (Sep. 9, 2021, 7:00 AM) <https://abcnews.go.com/US/texas-abortion-law-enforced/story?id=79879033>.

⁴⁸ REPRODUCTIVE LEGAL HELPLINE, *Abortion Laws FAQ*, <https://www.reprolegalhelpline.org/sma-faq/> (last visited Feb. 20, 2023).

⁴⁹ Shefali Luthra, *Abortion bans don’t prosecute pregnant people. That may be about to change*. THE 19TH (Jan. 13, 2023), <https://19thnews.org/2023/01/abortion-bans-pregnant-people-prosecution/>.

⁵⁰ Gabriela Weigel et al., *Criminalizing Pregnancy Loss and Jeopardizing Care: The Unintended Consequences of Abortion Restrictions and Fetal Harm Legislation*, 30 WOMEN’S HEALTH ISSUES 143, 144 (2020).

have charged individuals for the loss of their pregnancies for unintentionally falling downstairs or for *being* physically assaulted.⁵¹ Other laws allow the police to arrest people for failing to notify the police of stillbirth or miscarriage in a timely enough manner—including one instance where a woman was sentenced to six years in prison for waiting a few hours to report a stillbirth she experienced at home.⁵² Individuals experiencing pregnancy loss are also deterred from seeking mifepristone, even though it is an effective miscarriage treatment, because of the fear of criminalization due to the drug’s association with medication abortion.⁵³ These fears are now only amplified by efforts to outlaw medication abortion.⁵⁴

The impact of *Dobbs* is not only on individuals seeking care, but also on providers’ willingness to give care. As noted above, HHS has specifically requested comment on whether health care providers’ concerns about investigations into, or proceedings against, them or their patients bear negative effects.⁵⁵ Indeed, many reproductive health care providers are currently confused regarding the state of nationwide and state-level abortion regulations. This causes a chilling effect by which doctors are reluctant to deliver reproductive health care even where it would ostensibly be legal, such as in an emergency. In particular, Black physicians and other physicians of color face the highest threat of criminal prosecution under restrictive abortion bans, further limiting the ability for Black patients to receive culturally competent care.⁵⁶

The current legal framework in many states has created a situation where providers feel obligated to wait for patients to become sufficiently ill to treat them with abortion, even if such treatment is explicitly legal under national law, such as the Emergency Medical Treatment and Active Labor Act (EMTALA).⁵⁷ Strengthening the Privacy Rule

⁵¹ Gabriela Weigel et al., *Understanding Pregnancy Loss in the Context of Abortion Restrictions and Fetal Harm Laws*, KFF (Dec. 4, 2019), <https://www.kff.org/report-section/understanding-pregnancy-loss-in-the-context-of-abortion-restrictions-and-fetal-harm-laws-issue-brief/>.

⁵² *How My Stillbirth Became a Crime*, N.Y. TIMES (Dec. 28, 2018), <https://www.nytimes.com/interactive/2018/12/28/opinion/stillborn-murder-charge.html>.

⁵³ Katy B. Kozhimannil et al., *Modeling the Cost-Effectiveness of Doula Care Associated with Reductions in Preterm Birth and Cesarean Delivery*, 43 BIRTH 20 (2016).

⁵⁴ See [What to know about the lawsuit aiming to ban medication abortion drug mifepristone | CNN Politics](#); see also Amanda Allen & Cari Sietstra, *Miscarriages Are Awful, and Abortion Politics Make Them Worse*, THE N.Y. TIMES, (June 22, 2021) <https://www.nytimes.com/2021/06/22/opinion/miscarriage-abortion.html>.

⁵⁵ NPRM at 23,534.

⁵⁶ Adia Harvey Wingfield, *Abortion Bans Criminalize Doctors. For Black Physicians, the Risks are Even Higher*, VOX (Mar 3, 2020), <https://www.vox.com/first-person/2020/3/3/21162896/supreme-court-abortion-black-doctors-admitting-privileges>

⁵⁷ Pub. L. No. 99–272, 100 Stat. 164 (Apr. 7, 1986) (codified at 42 U.S.C. 1395dd). See e.g., Selena Simmons-Duffin, *For doctors, abortion restrictions create an ‘impossible choice’ when providing care*, NPR (June 24, 2022), <https://www.npr.org/sections/health-shots/2022/06/24/1107316711/doctors-ethical-bind-abortion>; Elizabeth Cohen & John Bonifield, *Texas woman almost dies because she couldn’t get an abortion*, CNN (Nov 16, 2022), <https://www.cnn.com/2022/11/16/health/abortion-texas-sepsis/index.html>.

to give doctors clear grounds for proceeding with treatment without fear that information about that treatment will be used for investigatory or enforcement purposes could be crucial to the provision of timely medical care and, in many instances, to saving lives.

The Proposed Rule is an important step toward preventing unwarranted disclosure and misuse of patients' reproductive health information as a tool for law enforcement. As HHS has recognized in the NPRM, disclosures of PHI that may currently be made without an individual authorization may lead to such misuse. This could occur where PHI disclosures are made for law enforcement purposes, in the context of judicial or administrative proceedings, or even in the context of health oversight activities. For example, 16 states currently require abortion providers to give some information on the patient's reasoning for seeking the abortion procedure; six states require providers to report whether the fetus was viable; and 14 states require providers to indicate whether state mandates for abortion counseling and parental involvement were satisfied.⁵⁸ Anti-abortion advocates have a history of advocating for reporting requirements ostensibly for public health purposes but that in fact may have the opposite effect.⁵⁹

Post-*Dobbs*, these reporting requirements pose a significant risk to individuals' rights to seek health care without facing criminalization, and have a disparate impact on Black communities and other marginalized communities.⁶⁰ Undocumented immigrants, for example, have expressed unease regarding leaving their states to seek legal abortion care for fear of deportation.⁶¹ The Proposed Rule is a means to preserve the rights of all persons in need of reproductive health care to obtain that care without fear of unwarranted investigations or prosecution.

II. The Proposed Rule Appropriately Balances Patient Privacy With the Benefits of Legitimate, Non-harmful Disclosures of PHI.

The Proposed Rule's prohibition on uses and disclosures of PHI in the circumstances set forth in proposed 45 C.F.R. § 164.502(a)(5)(iii) (the "Prohibited Circumstances") appropriately balances the need for disclosures for criminal, civil, or

⁵⁸ *Abortion Reporting Requirements*, GUTTMACHER INSTITUTE, <https://www.guttmacher.org/state-policy/explore/abortion-reporting-requirements> (last visited Feb. 20, 2023).

⁵⁹ Joerg Dreweke, *Abortion Reporting Promoting Public Health, Not Politics*, GUTTMACHER POLICY REVIEW (June 18, 2015), <https://www.guttmacher.org/gpr/2015/06/abortion-reporting-promoting-public-health-not-politics>.

⁶⁰ *See*, Liza Fuentes, *Inequity in US Abortion Rights and Access: The End of Roe Is Deepening Existing Divides*, THE GUTTMACHER INSTITUTE (Jan. 17, 2023), <https://www.guttmacher.org/2023/01/inequity-us-abortion-rights-and-access-end-roe-deepening-existing-divides> (explaining that the increase of abortion restrictions since *Dobbs* is layered on top of health care and economic systems that fail Black, Indigenous, and Latino communities, as well as low income communities. Thus, abortion bans and other restrictions harm people existing in those and intersection communities at higher rates).

⁶¹ Sofia Ahmed, *Abortion Worries Heightened for Unauthorized Immigrants in the U.S.*, REUTERS (Jul. 5, 2022, 12:50 PM), <https://www.reuters.com/world/us/abortion-worries-heightened-unauthorized-immigrants-us-2022-07-05/>.

administrative investigations or proceedings that further legitimate public policy goals, on the one hand, with patients' rights to privacy, on the other. We note, as HHS has pointed out, that the Proposed Rule does not provide individuals with the option to override the proposed prohibition by expressly authorizing the disclosure of their own PHI in the Prohibited Circumstances. In Section IV.B.4 of the NPRM, HHS has specifically requested public comment about whether individuals should have that option and, if so, whether there are means to prevent individuals from being coerced into providing such authorization.⁶²

Generally, the Lawyers' Committee believes that individuals should have the maximum amount of knowledge and control regarding their personal information, and that the Privacy Rule should not be amended in a way that would undermine those principles. However, with respect to individual's option to authorize disclosure of their PHI in the Prohibited Circumstances through the signing of a form, HHS has taken the prudent approach in not providing for such an option. In these particular circumstances, there are solid grounds for not relying on individual consent to protect patient privacy.⁶³ In the reproductive health setting, individuals are frequently subject to stress, fear, or duress, all of which could contribute to their providing an authorization against their will. Granting patients the right to authorize uses and disclosures of their PHI in the Prohibited Circumstances is unnecessary and potentially harmful.

First, permitting such authorizations would potentially cause harm by leading to unintended disclosures of PHI. The individuals most likely to be affected by investigations of reproductive health care may be the least likely to have the resources (including language proficiency) to understand the consequences of an authorization for disclosure of their PHI. For members of some historically marginalized communities, the multiple forms that they are asked to review and sign at a doctor's office may be difficult to understand, particularly if English is not the patient's first language—as is the case for many individuals subject to potential surveillance, such as undocumented immigrants. The inclusion of an authorization for disclosures of PHI in the Prohibited Circumstances among such documents could be confusing and misleading.

Indeed, such forms may be difficult to understand even for individuals who do attempt to read them and do have proficiency in English. As one study found, there are multiple reasons why patients may not read consent forms provided to them for signature.⁶⁴

⁶² NPRM at 23,534 (listed as question j).

⁶³ Indeed, notice and consent can be a misguided approach to privacy protection in other circumstances where consumers cannot be expected to have the necessary knowledge or resources to make informed privacy choices. *See, e.g.*, Turow, J., Lelkes, Y., Draper, N. A., & Waldman, A. E., *Americans Can't Consent To Companies' Use Of Their Data*, 1-24 UNIV. PA. ANNENBERG SCH. COMMC'N (2023), retrieved from https://repository.upenn.edu/asc_papers/830.

⁶⁴ *See* Ozhan, Mehmet Özgür et al., "Do the patients read the informed consent?" 31 BALKAN MED. J. 2 132-6 (2014), doi:10.5152/balkanmedj.2014.13212 (finding that study (mean age: 38.1 years; 63.8% male, 36.2% female). Overall, 54.8% of patients reported that they did not read the informed consent. Among them, 50.3% did not care about it because they thought they would have the operation anyway, 13.4% did not have enough time to read it, 11.9% found it difficult to understand, 5.9% could not read because they

Even for well-educated patients, there is a tendency to sign forms when presented with them in the health care context.⁶⁵ Some patients may assume such execution to be mandatory—even in the case of authorizations that, in accordance with the Privacy Rule, explicitly state that treatment and payment for treatment are not conditioned on signing the authorization. Our concern is that, if the Privacy Rule permitted patients to authorize disclosures of their PHI in Prohibited Circumstances, anti-abortion rights organizations might disseminate template authorizations for distribution among one of many documents that patients routinely sign, often without a full understanding of what they are consenting to.

Second, permitting such authorizations is not necessary to preserve patients' rights to control covered entities' use and disclosure of patient PHI. Given individuals' right to access their PHI held by covered entities, patients who wish to permit disclosures of their PHI in Prohibited Circumstances can do so by requesting copies of the PHI and providing the information themselves for the relevant investigation or proceeding. To the extent this is a patient's choice, that choice can be exercised without providing an authorization. In Section IV.B.4 of the NPRM, HHS has asked if there is a possibility that patients might be coerced into obtaining their PHI through such access requests and then providing it for use in the Prohibited Circumstances.⁶⁶ This potential coercion is a concern, and we urge that HHS address it by, at a minimum, requiring the patient requesting access to attest that their access request is being freely and voluntarily made. Although this may not rule out the possibility of coercion, it would at least provide a gating mechanism to help prevent access requests from being used to circumvent the prohibition on disclosures in the Prohibited Circumstances.

HHS has suggested that attestations also might be a condition of permitting patient authorizations for disclosures in the Prohibited Circumstances subject to certain conditions: specifically, if a covered entity should be permitted to rely on a patient authorization in this context only if the authorized recipient of the PHI provides an attestation regarding the permissible uses and disclosures of the PHI.⁶⁷ We view this as preferable to allowing disclosures based on authorizations alone, but the optimal approach is the one taken by HHS in the Proposed Rule: *i.e.*, prohibiting such disclosures without exception, other than to the individual to whom the PHI pertains.

had no glasses with them, and 5.2% found it frightening and gave up reading. Inpatients, older patients and patients with co-morbidities were less likely to read the informed consent document than outpatients, and younger and healthy patients ($p < 0.05$). Also, 57.9% of parents whose children would be operated on had read the document.

⁶⁵ *See id.*

⁶⁶ NPRM at 23,534.

⁶⁷ *Id.*

III. The Proposed Rule Should Clarify the “Minimum Necessary” Standard to Increase Transparency and Ensure Data Minimization.

Data minimization is a leading principle of most privacy regimes globally. The first way to combat harms from unwarranted uses of personal data is to collect less data. HHS recognized this principle in creating the “minimum necessary” standard in the Privacy Rule, which applies to both uses and disclosures of PHI. Limiting the amount of PHI that covered entities and their business associates process can prevent disclosures of PHI that may be discoverable or otherwise available in Prohibited Circumstances. This is particularly important for members of Black communities. In physical as well as online spaces, Black people in America experience “multiple forms of excessive and discriminatory surveillance.”⁶⁸ Minimizing the collection, use, and sharing of PHI (as well as other personal data) is an important step in combatting such discriminatory surveillance practices.

The NPRM highlights the importance of the “minimum necessary” requirement for permissible disclosures of PHI under the Privacy Rule in the current reproductive health care environment. HHS has not proposed to alter the “minimum necessary” standard, but its final Privacy Rule revisions should clarify the standard with respect to PHI related to reproductive health care.

First, it would be helpful for HHS to further clarify the parameters of the minimum necessary standard in the reproductive health context. HHS might consider ways in which it can further assist with standardization of information for disclosure under the minimum necessary rule, such that patients have a better understanding of what might be disclosed under the rule. These types of clarifications will benefit individuals seeking reproductive care by providing them with an appropriate level of transparency, a key foundation for trust.

Second, HHS should clarify how the Privacy Rule addresses data retention, which is inherently related to data minimization. The Privacy Rule does not, in fact, contain data retention requirements aside from requirements to retain certain policies, procedures, and records of compliance-related actions for six years. The six-year retention requirement is misunderstood by many, however, to apply to PHI. Consistent with the minimum necessary principle and the widely accepted privacy principle of data storage limitation, we urge HHS to clarify in the final Privacy Rule modifications, and in other guidance, that the Rule’s data retention requirements do not apply to PHI. This clarification will serve the purposes of the Proposed Rule by reducing the retention of PHI related to reproductive health on erroneous grounds, subject, of course, to applicable state law record retention requirements.

IV. Conclusion

In sum, we encourage HHS to consider the disparate impacts of criminalization and surveillance, the effect that such actions have on alienating Black communities and other

⁶⁸ Anita L. Allen, *Dismantling the “Black Opticon”: Privacy, Race Equity, and Online Data Protection Reform*, YALE L.J.F. 907, 910 (Feb. 2022).

historically marginalized communities from healthcare providers, and how that alienation contributes to negative health outcomes for marginalized people in promulgating a final rule. Misuse of reproductive-related PHI, especially in a criminal context, will deter the provision of necessary reproductive health care, especially in communities that already face obstacles in accessing quality reproductive healthcare. We support and urge the adoption of the Proposed Rule to help prevent such misuse.

We also urge HHS to consider, in the future, promulgating broader rules in this area. Current state- and nation-wide regulations on reproductive health, abortion care, and gender-affirming care create a complicated web of enforcement wherein actions that are legal in one state are not legal in a neighboring state. While we appreciate HHS's justifications for focusing on legally obtained care, we advocate that there is no meaningful difference between illegal and legally obtained care beyond arbitrary distinctions in many cases. A rule to protect pregnant people more fully should eliminate those distinctions and protect all forms of reproductive health care from criminalization and government investigation.

Thank you for your attention to and consideration of these comments. Please do not hesitate to contact Kathryn Youker at kyouker@lawyerscommittee.org or David Brody at dbrody@lawyerscommittee.org if you have any questions.

Sincerely,

Lawyers' Committee for Civil Rights Under Law

By: /s/ Kathryn Youker

Kathryn Youker,

Director, Economic Justice Project

David Brody,

Managing Attorney, Digital Justice Initiative

Arnold & Porter Kaye Scholer, LLP

Counsel to the Lawyers' Committee for Civil Rights Under Law

Nancy Perkins

Emily Dorner

Annie Blackman