



Planned Parenthood Federation of America, Inc.

June 16, 2023

**VIA ELECTRONIC TRANSMISSION**

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

Dear Director Rainer,

Planned Parenthood Federation of America (Planned Parenthood) is pleased to submit these comments in response to the Notice of Proposed Rulemaking (proposed rule, NPRM), “HIPAA Privacy Rule To Support Reproductive Health Care Privacy,” released by the Department of Health and Human Services (HHS) Office for Civil Rights (OCR) on April 12, 2023 and published in the Federal Register on April 17, 2023.<sup>1</sup> As a trusted voice for sexual and reproductive health, Planned Parenthood appreciates the opportunity to weigh in on policy proposals that impact the communities our affiliates serve across the country.

Planned Parenthood is a leading advocate for policies advancing access to sexual and reproductive health care. Planned Parenthood affiliates are trusted nonprofit sources of primary and preventive care for people of all genders in communities across the country. Planned Parenthood health centers provide affordable birth control, lifesaving cancer screenings, testing and treatment for sexually transmitted infections and other essential care to 2.1 million patients annually. Planned Parenthood health centers also provide abortion services and ensure that all people have accurate information about all of their reproductive health care options. One in five women in the United States has visited a Planned Parenthood health center. The majority (more than 70%) of Planned Parenthood patients have incomes at or below 150 percent of the Federal Poverty Level (FPL). Planned Parenthood Federation of America works on behalf of its affiliates and their patients and communities as a leading advocate for access to the full range of sexual and reproductive health care for all.

The *Dobbs v. Jackson Women’s Health Organization* Supreme Court decision in June 2022 ended the federal constitutional right to abortion after nearly 50 years and allowed states to ban abortion.<sup>2</sup> Following the decision, states have enacted a patchwork of abortion bans that have led to significant confusion for patients and some providers regarding what information related to pregnancy outcomes can or must be shared with law enforcement.<sup>3</sup> OCR shared helpful

<sup>1</sup>HIPAA Privacy Rule To Support Reproductive Health Care Privacy (2023).

<sup>2</sup>*Dobbs v. Jackson Women’s Health Organization* (United States Supreme Court June 24, 2022).

<sup>3</sup>*Human rights crisis: Abortion in the United States after Dobbs*. Human Rights Watch. (2023, April 18).

[https://www.hrw.org/news/2023/04/18/human-rights-crisis-abortion-united-states-after-dobbs#\\_Toc132207](https://www.hrw.org/news/2023/04/18/human-rights-crisis-abortion-united-states-after-dobbs#_Toc132207)

guidance in 2022, clarifying that information related to abortion is not required to be disclosed to law enforcement or state entities under the Health Insurance Portability and Accountability Act (HIPAA), regardless of state law.<sup>4</sup> However, under HIPAA and the 2022 guidance, providers can still share this information as a discretionary disclosure.

Expanding privacy protections for protected health information (PHI) and other sensitive health related data is essential to protect patients and providers from investigation or prosecution for receiving or providing lifesaving health care. Tightening HIPAA is not the only way in which patient data must be made more secure, but it is an essential element. HIPAA's current patient consent exceptions for disclosures to law enforcement or for legal proceedings must be amended to protect both patients and their providers. This proposed rule takes integral steps toward this goal within current law, and we commend OCR for undertaking this important effort. In these comments, Planned Parenthood expresses support for several components of the proposed rule and makes recommendations to strengthen it. Planned Parenthood urges OCR to move swiftly to finalize the rule in its proposed form, considering these proposed additions and recommendations.

#### **I. Planned Parenthood strongly supports this proposed rule and commends OCR for taking decisive action to protect patients, providers, and their loved ones**

Planned Parenthood applauds OCR for taking this step to keep PHI confidential when states or other non-HIPAA-regulated entities seek to use it to investigate, prosecute, or otherwise take administrative or civil action against patients, providers, or those facilitating access to reproductive health care. The proposed rule is responsive to many of the concerns expressed by organizations representing both patients and providers. If implemented effectively, this rule will better protect both patients and providers, and support confidentiality within the health care system. Planned Parenthood encourages OCR to finalize the following provisions.

##### **A. Maintain a broad definition of reproductive health care**

Planned Parenthood strongly supports OCR's proposed broad definition of reproductive health care. Reproductive health care is not a narrow list of services provided by an OB/GYN; rather, as OCR rightly acknowledges, there is a great range of care and services that can be provided in connection with a person's reproductive health. It cannot be limited by gender, age, sexual identity, or provider type. As medical science and technology advance, it is important that the definition be able to encompass comprehensive reproductive health care in all forms. In addition, a broad definition places trust and discretion in the hands of professional health care providers to determine what information is and is not related to their patients' reproductive health and meets the criteria listed in the rule. For example, a primary care provider may

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236 ; *State bans on abortion throughout pregnancy*. Guttmacher Institute. (2023, June 7). <https://www.guttmacher.org/state-policy/explore/state-policies-later-abortions>

<sup>4</sup>Assistant Secretary for Public Affairs (ASPA). (2022, June 29). *HHS issues guidance to protect patient privacy in wake of Supreme Court decision on Roe*. HHS.gov. <https://www.hhs.gov/about/news/2022/06/29/hhs-issues-guidance-to-protect-patient-privacy-in-wake-of-supreme-court-decision-on-roe.html>

discuss a patient's contraceptive use during an overview of their medications, or a patient may see an endocrinologist for polycystic ovary syndrome, a condition impacting fertility.

Planned Parenthood encourages OCR to keep this definition in its final rulemaking and not delineate specific services that qualify for protection under the rule. Narrowing the definition based on specific services or patient populations could exclude relevant types of care and harm any omitted groups. For example, patients with specific care needs, like those with disabilities or genetic risk factors or those who utilize translation services, may not be properly accommodated by a generic list of more common services. Attempting to generate a comprehensive list seems most likely to leave out those who already face the most barriers to accessing care. Delineation could also lead to a chilling effect on patients seeking care if they cannot be sure their PHI would be protected from external access.<sup>5</sup> It would also reduce the needed discretion for reproductive health care providers to determine what fits within the definition.

### **B. Maintain the protections for providers, patients, and their assisters**

One of the strengths of this proposed rule is the breadth of individuals it protects from investigations and legal or administrative action regarding their involvement in reproductive health care. Just as patients may fear sharing their sensitive information, providers are also operating in uncertainty as to whether they will be unjustly targeted for providing care that is both legal and necessary for their patients.<sup>6</sup> In addition, some states have passed laws allowing legal action against individuals who assist or facilitate someone in accessing reproductive health care.<sup>7</sup> It is essential that all of these populations are protected under the final rule in order to maintain access and reduce the chilling effect on individuals' accessing or providing care. Therefore, Planned Parenthood strongly encourages OCR to keep the scope of the proposed rule, which extends privacy protections to data that may be used in connection with a criminal, civil, or administrative investigation or proceeding against the individual, their health care provider, or others.

### **C. Maintain the clear explanations of proper and improper uses of reproductive health care data**

Planned Parenthood appreciates the clear explanations in the proposed rule preamble that flesh out conduct that would be considered prohibited data usage, including examples of how public officials could access data for prohibited purposes. For example, OCR responded to sexual and reproductive health care provider and advocate concerns that state entities use public health oversight powers to access and misuse reproductive health data. Department of Health officials in Missouri used this tactic in 2019. In an attempt to track abortion patients at Planned Parenthood health centers, public employees gathered menstrual cycle data reported by providers to estimate which patients may have been pregnant.<sup>8</sup> The proposed rule preamble

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<sup>5</sup>Terry, N. P. (2023, January 9). *How Dobbs threatens health privacy*. Bill of Health. <https://blog.petrieflom.law.harvard.edu/2023/01/10/how-dobbs-threatens-health-privacy/>

<sup>6</sup>*Human rights crisis: Abortion in the United States after Dobbs*. Human Rights Watch. (2023, April 18).

<sup>7</sup> Ibid

<sup>8</sup> Simon, D. (2019, October 31). *Missouri says health director didn't track Planned Parenthood Patients' periods. but officials did have a spreadsheet*. CNN.

states that public health uses of data should not require identifiable, individual level data and should remain separate and distinct from law enforcement uses of PHI.<sup>9</sup> This language makes clear that such a use of specific, patient level data to investigate providers would not be permissible under this rule if finalized, and Planned Parenthood strongly agrees with and supports this approach. Government officials should not be permitted to collect patient reproductive health data under the auspices of engaging in public health campaigns but then use the data for individual investigations of patients and/or providers.

Similarly, as the proposed rule preamble makes clear, the act of seeking, obtaining, providing, or facilitating reproductive health care is not and should not be considered “child abuse,” as referenced as an instance in which state reporting laws may preempt HIPAA in the Privacy Rule. This is important to clarify, given anti-abortion politicians have insinuated that abortion recipients could be prosecuted as child abusers. For example, Attorney General Steve Marshall of Alabama has declared that the state will prosecute individuals who access medication abortion under the state’s chemical endangerment statute (a deeply incorrect application of the law).<sup>10</sup> Many states have chemical endangerment statutes like this, intended to protect infants and children from unsafe and unhealthy environments where illicit substances are created or distributed (such as home labs creating methamphetamine products).<sup>11</sup> These laws were not designed to punish pregnant people for accessing health care like medication abortion, yet some state actors are weaponizing these laws in exactly this way. The Alabama chemical endangerment statute has already been used to prosecute pregnant people who used drugs during pregnancy, and the legal theory Marshall put forth would be an expansion of that use.<sup>12</sup> Planned Parenthood recommends that the final version of this rule continue to make clear that accessing care is not itself a form of child abuse. Therefore, requesting entities – especially state administrative or law enforcement agencies – should not be able to use such reasoning to negate the protections afforded by the proposed rule and obtain reproductive health-related PHI without consent.

## **II. Planned Parenthood offers recommendations to further strengthen this rule and expand its reach to benefit as many patients and providers as possible**

These recommendations relate to both the content of the data that should be protected under the rule and the circumstances under which requesting entities should and should not be granted access to that data.

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<https://www.cnn.com/2019/10/31/us/missouri-health-director-planned-parenthood/index.html>; the state claimed “it grew concerned it may not be receiving complication reports for all failed surgical abortions” and Health Director Dr. Randall Williams testified that he “tracked the patients’ menstrual cycles with a spreadsheet...compiled at Williams’ request by the state’s main inspector.”

<sup>9</sup>HIPAA Privacy Rule To Support Reproductive Health Care Privacy, Section 23526.

<sup>10</sup>Mizelle, S., & Boyette, C. (2023, January 12). *Alabama attorney general says people who take abortion pills could be prosecuted* | CNN politics. CNN.

<https://www.cnn.com/2023/01/12/politics/alabama-abortion-women-prosecution/index.html>

<sup>11</sup>Alabama Code 1975, Section 26-15-3.2. Chemical Endangerment of a Child.

<sup>12</sup> Pregnancy Justice. (2022). *Confronting Pregnancy Criminalization*.

**A. OCR should ensure all reproductive health care is protected by defining reproductive health care at the encounter rather than service level for the purposes of disclosures**

Any health care visits or encounters (defined as a single insurance claim or entry in the patient's health care record) that include some kind of reproductive health care service and therefore generate reproductive healthcare data that falls under the proposed rule should be considered reproductive health care visits. Therefore, data relating to all services provided or discussions held during such visits should be protected for the purposes of this rule. Effectively, this would mean that any health data generated during a patient encounter that includes reproductive health care services should be protected as part of the final rule. It is operationally difficult to separate out data within a visit, and it would create a practical burden on providers to segregate data based on specific services when responding to a request that falls under this rule.

Additionally, patients must feel comfortable discussing all their questions and concerns with their providers, whether directly related to their reproductive systems or not, and especially when related to stigmatized conditions. For example, pregnant patients may be reluctant to seek substance use treatment, mental health treatment, or acknowledge assault with providers if they fear that information may be shared externally and used against them in criminal or civil actions.<sup>13</sup> All reproductive health care patients deserve the same level of protection from their records being used against them in the ways this rule seeks to prevent.

As such, we believe that all patient data from any visit that generates reproductive health data should be entirely protected from disclosure under this rule. While this step would incorporate a great deal of health care data that is not necessarily directly related to reproductive health, failure to do so would have significantly worse consequences. Primary care providers keep a list of a patient's medications that may include contraception, for example, and may track patients' menstrual cycles and pregnancy status. Excluding that PHI from this rule's protections would maintain an unnecessary and potentially dangerous loophole, and, as discussed above, it is operationally burdensome to separate out data within a single encounter. As such, this expansion of the proposed rule's protections is necessary and worth any additional burden.

OCR should add to its definition of reproductive health care the following: "for the purposes of disclosures under this rule, a regulated entity should treat all data from an episode (encounter, visit) of care as a single unit of PHI. As such, if that unit contains any service related to reproductive health care, the full unit of PHI is subject to the protections and requirements of this rule."

**B. OCR should strengthen attestation requirements concerning lawfulness of care to support regulated entities' compliance with the rule**

The proposed rule reaches reproductive health care that "is lawful in the state in which it is provided." The complex web of state laws relating to the broad scope of reproductive health<sup>14</sup>

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<sup>13</sup>Ibid.

<sup>14</sup>Concerning abortion provision, age of consent for contraception, informed consent, provider licensure and scope of practice, etc.

will make determinations about “lawfulness” incredibly burdensome for regulated entities facing requests for PHI. That assessment would be particularly challenging in cases where the covered entity receiving the request for data is not the entity that provided the care in question. Ultimately, entities in different states or with different interpretations of certain state requirements may reach different determinations about what care was “lawfully” provided.

To address this concern, Planned Parenthood believes that the attestation requirements must be amended to give regulated entities more detail concerning the grounds under which a requesting entity is requesting data. Specifically, attestations should include a simple statement where a requesting entity would indicate whether or not it seeks PHI in order to investigate, prosecute, or take administrative action against a patient, provider, or assister in connection with care the requestor believes was unlawfully provided. The regulated entity would then at least be aware that the lawfulness of care was at issue and could better evaluate the validity of the attestation. This approach would also allow regulated entities to significantly limit resources expended evaluating attestations, creating a sub-category for more specific review.

In addition, OCR should clarify that the lawfulness of care is dependent solely upon the laws and regulations within the jurisdiction where the care was provided.

#### **C. OCR should require requesters to be specific in the PHI they are requesting**

OCR should require any non-HIPAA-regulated entities requesting PHI to be specific in their requests regarding what PHI they are seeking, including the exact patient and visit date. These requesters must not be permitted to “fish” for data that they would not otherwise know to request, such as every prenatal patient at a health center during a given month. Such “fishing expeditions” would open the door for investigations, prosecutions, or administrative or civil actions and would run counter to the desired effect of the rule. Health care organizations and individual providers should be required to reject any request that does not name a specific patient and visit date. Limiting permissible requests to a single visit confirms that the requester knows what they are looking for when making the request, rather than seeking records broadly in hopes of initiating legal or administrative action against the patient or provider.

#### **D. OCR should strengthen the attestation requirements to prevent third parties from misusing PHI**

Planned Parenthood also recommends that OCR include more robust attestation requirements to prevent any misuse of reproductive health data. While HIPAA does not govern how a third party entity uses data once it leaves a covered entity, OCR can tighten the requirements at the time the covered entity is asked to release the data. The proposed rule requires entities requesting data to attest that conducting an investigation, prosecution, or civil or administrative action is not the primary reason they are requesting a patient’s record. However, it seems reasonably foreseeable that a requesting entity could still use the PHI for one of these otherwise prohibited purposes once they have it. As long as it was not the *primary* purpose for their request, they could still lawfully receive the PHI and then use it however they’d like. For example, a state or local health agency could claim to ask for data for health care-related purposes while also planning at that time to use it in a prohibited action, such as sharing it with

a child and family services agency to remove the patient's children from their custody or with law enforcement to pursue criminal action.

Planned Parenthood strongly recommends that OCR require requesting entities to attest that they do not intend to use the PHI for an otherwise prohibited purpose, whether it is a primary or secondary use. Thus the HIPAA-regulated entity receiving the request may be confident that the data will not be used in a fashion that runs counter to the rule's intent. Planned Parenthood also believes the attestation form should be required to list out the prohibited purposes for data, so the requesting entities more directly confirm how the data may not be used, and cannot claim to have misunderstood any prohibited purposes.

#### **E. OCR should add specific data protections for gender affirming care**

As stated above, Planned Parenthood strongly supports the existing definition of reproductive health care. However, gender affirming care (GAC) is another increasingly criminalized type of health care for which governmental entities are seeking data to investigate or penalize people based on the forms of life-affirming care they seek or provide. There are already 20 states that have criminalized accessing and/or providing forms of gender affirming care.<sup>15</sup> Multiple of these state laws limit access to care for adults, but they all most dramatically impact gender affirming care for minors. These laws threaten not only the licenses of providers offering GAC but the parents who seek this often-life-saving care for their minor children.<sup>16</sup>

State level attacks on health care for transgender people parallel those on abortion care, including in their escalation following the *Dobbs* decision. The proliferation of these bans leads to similar concerns with respect to the misuse of health data for law enforcement purposes, and, as written, the proposed rule does not protect all gender affirming care data from disclosure without consent. Because much transgender health care is a category distinct from and broader than reproductive health care, it should be addressed explicitly and separately in the final rule text or subsequent rulemaking.

One approach would be to create a distinct category of transgender health care, similar to how the NPRM creates the category of reproductive health care, in order to afford it special protections. This would be added as a new definition in 45 CFR § 160.103.

#### **F. OCR should work with other agencies to create penalties for violations of the rule by requesters**

Planned Parenthood understands that OCR's primary enforcement power is against the misuse of PHI by covered entities and their business associates. We appreciate the need to ensure that HIPAA-regulated entities do not disclose data inappropriately; however, it is also vital to ensure that regulated entities do not receive inappropriate enforcement actions when requesting entities do not adhere to their attestations, as described above. When the regulated entity has a

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<sup>15</sup> *Attacks on gender affirming care by state map*. Human Rights Campaign. (n.d.). <https://www.hrc.org/resources/attacks-on-gender-affirming-care-by-state-map>

<sup>16</sup> Redfield, Elana et al|. (2023, April 6). *Prohibiting gender-affirming medical care for Youth*. Williams Institute. <https://williamsinstitute.law.ucla.edu/publications/bans-trans-youth-health-care/>

good faith belief that it is operating in compliance with the rule, it should not be held responsible for the actions of the requesting entity. OCR should collaborate with other offices within HHS and the Department of Justice to define enforcement measures against governmental and nongovernmental entities that renege on their attestations and work counter to the intent of this rule. Such measures should accompany a final version of this rule as quickly as possible.

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Planned Parenthood would like to thank OCR for the opportunity to offer comments on this deeply important piece of rulemaking. We strongly encourage OCR to implement our suggestions to strengthen the rule and move quickly to finalize it. Patients, providers, and their loved ones need and deserve the protections this rule will afford them, as soon as possible. Planned Parenthood appreciates the opportunity to continue to serve as a thought partner with OCR as the Office begins finalizing and implementing the regulation. Please contact me with any questions.

Sincerely,

A handwritten signature in black ink, appearing to read "Laurel Sakai". The signature is fluid and cursive, with a large initial "L" and "S".

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