Final HIPAA Privacy Rule Adds New Protections for Reproductive Health Care Data

On April 22, 2024, the Administration released a final rule strengthening privacy and confidentiality protections for reproductive health data under the federal Health Insurance Portability and Accountability Act (HIPAA). This rule is one of the many actions the Administration has taken to shore up reproductive health care access in the wake of the Supreme Court’s decision in *Dobbs vs. Jackson Women’s Health Organization*, which overturned the constitutional right to abortion in the United States. The privacy rule released earlier this week adds important new protections limiting the circumstances under which reproductive health care data can be released in connection with the criminalization of abortion and other services. The rule does not, however, protect reproductive health care data in all circumstances.

In addition to the breakdown below, join CHLPI in conversation with experts from the Network for Public Health Law, Pregnancy Justice, and the Center for HIV Law and Policy on May 2 at 3 pm ET. Speakers will share a digestible overview of the final rule, initial reflections on strengths and limitations, and an understanding of on-the-ground implications. Register here.

Why Did the Administration Need to Amend HIPAA After Dobbs?

HIPAA is a sweeping federal law passed in 1996 that includes a privacy and confidentiality provision for patient health records and data. HIPAA’s privacy protections prohibit “covered entities” from releasing protected health information (PHI) of patients unless the use or disclosure of that information is allowed under an exception.
One of the longstanding exceptions that allows covered entities to release PHI without a patient’s consent is in response to a subpoena or court order pursuant to law enforcement. The Dobbs decision has triggered a wave of state laws criminalizing abortion. Providers, patients, and policymakers have been concerned that without adequate data privacy protections, people are deterred from necessary reproductive health care – including contraception, family planning services, and abortion services – out of fear that sensitive health information regarding abortion care will be shared with law enforcement. There has been particular concern about the need to protect data when a patient travels from a state with an abortion ban to a state with legalized abortion to receive care, an occurrence that is becoming more and more common as interstate travel for abortions increases.

What Privacy Protections for Reproductive Health Care Does the New Rule Include?

The new rule makes several clarifications about how HIPAA applies to reproductive health care data, while underscoring that the same principles that undergird the entire HIPAA privacy framework apply to the new protections as well. At its core, HIPAA involves a careful balance of the privacy interests of patients with the interests of society in accessing certain information for non-health purposes. The rule attempts to achieve this balance with the following new provisions:

- **Prohibits specific uses and disclosures of some reproductive health care data**

  The rule states that HIPAA covered entities may not release or use PHI to conduct a criminal, civil, or administrative investigation or impose liability on any person “for the mere act of seeking, obtaining, providing, or facilitating reproductive health care.” The rule provides two scenarios to which this protection applies:
When reproductive health care is legal in the state in which it is obtained

- Example: Reproductive health care is legally obtained in a state where abortion is legal, and the investigation originates in the state the patient lives where the service would have been illegal.

- Example: The reproductive health care at issue is obtained legally in a state and the investigation originates in that state.

When reproductive health care is obtained legally under a federal law that preempts state criminal laws prohibiting abortion

- Example: Someone receives care for a miscarriage that a hospital must provide under the federal Emergency Medical Treatment and Labor Act (EMTALA).

The final rule requires covered entities to obtain a signed attestation from the entity requesting the reproductive health care stating that the information will not be used for prohibited purposes. An attestation is required when the request for PHI is for health oversight activities, judicial and administrative proceedings, law enforcement purposes, or disclosures to coroners and medical examiners.

The clarifications to the HIPAA privacy rule do not prohibit release of reproductive health data in response to a subpoena or court order when the data request is related to *unlawful* receipt or provision of reproductive health care (i.e., data related to receipt of an abortion in a state that bans abortions before a certain gestational age). In that circumstance, the existing HIPAA exception and process for release of PHI in response to a law enforcement subpoena or court order would apply and the covered entity is permitted (but not required) to release the information as long as all other conditions are met.

Many will find it disappointing that the new rule only protects medical records of legal abortion care. This is a difficult compromise given widening disparities in access to abortion. At the same time, the Administration may have felt that more expansive protections would not have been legally defensible or practicable. It appears that the Administration tries to thread the needle in abortion-restrictive states by empowering health care providers to determine whether care is lawful and by creating a presumption of lawfulness. This allows a provider to use the medically necessary exceptions often found in state abortion bans to provide medically necessary abortion care and then to refuse to disclose records of this care to law enforcement.
• **Defines “public health” for purposes of HIPAA exception**

The HIPAA privacy rule has long allowed for disclosures of PHI for a range of public health activities, including public health surveillance. However, the rule never explicitly defined “public health.” The final rule adds a definition of public health to mean “population-health activities to prevent disease in and promote the health of populations ... [including,] identifying, monitoring, preventing, or mitigating ongoing or prospective threats to the health or safety of a population, which may involve the collection of protected health information.” The rule explicitly excludes criminal, civil, or administrative investigations for seeking obtaining, providing, or facilitating health care from this exception. The more specific definition of public health and the exclusion of investigations from this definition will help minimize the risk that public health is used as a blanket justification for otherwise impermissible disclosures of reproductive health data. However, the rule does allow state health departments to collect abortion information, including PHI, as part of public health activities as long as information collected is the “minimum necessary” to accomplish the public health goal.

• **Revises notice requirements**

The final rule requires covered entities to revise their Notice of Privacy Practices (NPPs) to include the new reproductive health privacy protections. This is important to ensure that patients are aware of their rights under the new rule.

**What’s Next?**

The regulation goes into effect 60 days after publication in the Federal Register and covered entities must be in compliance 180 days after the effective date. It is likely that HHS will develop a host of training material over the coming weeks and months to assist covered entities as they operationalize the new protections.

Beyond this rule, abortion care continues to be very much in the public spotlight and is also the subject of multiple lawsuits challenging state and federal laws. Litigation is proceeding in a handful of states challenging state abortion bans. Last month the U.S. Supreme Court heard oral arguments in a case challenging access to the medication abortion drug, mifepristone. This month the Supreme court heard oral arguments in a case about whether a federal law requiring hospitals to provide emergency care to stabilize patients allows for abortions in abortion-restrictive states. It is possible that the new privacy rule will also be the subject of litigation challenging the authority of HHS to carve out specific protections in

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**The Rule Did Not Expand Protections for Other Sensitive Data Subject to Law Enforcement Requests**

Several commenters requested that HHS expand its protections beyond reproductive health data to include other “highly sensitive,” data, including HIV health records, which can be the subject of law enforcement requests in states where HIV transmission is criminalized. Commenters argued that the same justifications for adding additional protections for reproductive health data apply to these other sensitive and highly stigmatized. HHS declined to create a broader protection, noting that doing so would introduce confusion, an impracticable administrative burden, and that there is lack of consensus on what this broader definition would encompass.
what has historically been a broadly applicable privacy regulation. This is a fast-moving issue and CHLPI will continue to provide updates as the policy and legal landscape evolve.