



Center for Public  
Representation

February 12, 2019

Mr. Roger Severino  
Director  
Office for Civil Rights  
U.S. Department of Health and Human Services  
Hubert H. Humphrey Building, Room 509F  
200 Independence Avenue SW  
Washington, DC 20201

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

Re: Request for Information (RFI) on Modifying HIPAA Rules To  
Improve Coordinated Care (RIN 0945-AA00)

Dear Director Severino,

Thank you for the opportunity to submit comments in response to the Request for Information on Modifying Health Insurance Portability and Accountability Act (HIPAA) Rules to Improve Coordinated Care from the U.S. Department of Health and Human Services (HHS) Office for Civil Rights (OCR). CPR is a national legal advocacy organization that promotes full inclusion and self-determination for people with disabilities, including people with mental health disabilities, in all aspects of life. We submit the following comments for your consideration.

Regarding the issue of whether OCR should modify or otherwise clarify provisions of the HIPAA (or “Privacy”) Rules to encourage covered entities to share protected health information (PHI) with non-covered entities when needed to coordinate care and provide related health care services and support for individuals, we recommend prioritizing the privacy and security of PHI, while educating providers on the existing limits and options under the existing law and regulations. Individuals have a strong interest in the protection of their PHI, and this interest may be heightened for a person who is experiencing or recovering from a health crisis. Overall, we urge OCR to continue the existing federal protections, and enhance them in places, so that individuals are able to maintain their dignity and autonomy within the health care system.

Feedback on specific inquiries:

**Question 13:**

Preserving individuals’ ability to control their information and how it is shared is a central priority of HIPAA, and we strongly discourage any changes that would override an individual’s request to restrict disclosures of their health information.

1825 K Street NW, Suite 600  
Washington, DC 20006  
202-854-1270

22 Green Street  
Northampton, MA 01060  
413-586-6024  
[www.centerforpublicrep.org](http://www.centerforpublicrep.org)

246 Walnut Street  
Newton, MA 02460  
617-965-0776

## Questions 18 & 19:

Health care providers are increasingly recognizing that successfully addressing patients' medical needs necessarily includes addressing other needs that impact their health. For instance, some patients lack adequate transportation to get to appointments or are forced to make difficult choices between paying medical bills and other necessities like food and rent. Many health care providers are tackling these issues by partnering with social service providers to improve access to healthy food, housing, transportation, education, job training and more. However, because of misconceptions and misinterpretations of the Privacy Rules, many others are not.

Providing more holistic care and addressing adverse social determinants of health requires health care and social service providers to share information, but we strongly believe this should not come at the expense of patient privacy. Fortunately, HIPAA already allows the exchange of patient information while also ensuring that this information remains protected and private. Unfortunately, perceived barriers and inconsistent interpretations by health care providers persist. Overcoming these perceived barriers is critical to increasing the willingness of partners to share data and provide more holistic, patient-centered care.

CPR does not support any changes to 45 CFR § 164.506 or that otherwise would expand the permitted uses or disclosure of PHI, and does not support any modifications to require disclosure of PHI for payment or health care operations purposes, either generally or for specific purposes. However, CPR does support a modification to require the provision of PHI for *treatment activities* in the specific instances where PHI is requested by a covered health care provider, where the request for the provision of such PHI has been made with the explicit affirmative authorization of the patient, where the PHI is requested for use in that patient's treatment, and where the patient has been given the opportunity to limit the request to specific PHI or timeframes.

Such a requirement may improve care coordination and/or case management where, for example, a patient is receiving care from multiple providers in different health systems that do not share health data electronically, or where a patient has switched providers and seeks her treatment records for her previous provider. Under current law, the requested provider may, but need not, provide PHI when requested. Because access to a patient's medical history may improve clinical decision-making and care coordination, we support a modification that such PHI be provided in a reasonable timeframe and in a format that is accessible to the requesting provider. However, we would support this change only if it is accompanied by a requirement that the patient has been informed that the requesting provider will be required to provide the information and has explicitly consented to the request for PHI. Because we believe any requirement should be limited to PHI related to treatment activities, we believe any change should be limited to covered health care providers.

CPR strongly opposes any changes that would permit or require the provision of PHI from a covered entity to a non-covered health care provider except on the condition that the request was initiated by the person whose PHI was requested and the non-covered health care provider provides explicit, enforceable, written assurance that they will follow all requirements as though

they were a covered entity. CPR strongly opposes the provision of PHI to any non-covered entity for any purpose other than treatment of the person whose PHI is requested.

Particularly for communities of color, PHI has historically been used against individuals, for example, to take away their children, housing, or economic opportunity, as often as it has been used to enhance care. In fact, racial and ethnic minorities show the greatest concern about the privacy of their medical records.<sup>1</sup> Therefore, CPR believes that all entities must be required to take reasonable efforts to limit the release of PHI to the minimum necessary to accomplish the task, including if that task is case management, care coordination, or claims management. If a covered entity needs PHI for purposes beyond those minimally necessary, the entity can and should obtain patient consent.

While CPR understands and appreciates the increasingly interdisciplinary nature of care delivery, again, we discourage changes that would permit disclosure of covered PHI to any non-covered entities except to clarify the existing Rules and to ensure that PHI may be provided only a) for the purposes of treatment; b) to an entity that has provided explicit, enforceable, written assurance that it will act as though it was subject to the Privacy Rules; and c) where the patient has provided explicit affirmative authorization for the PHI to be disclosed, including the specific PHI to be disclosed, the specific timeframe covered, and the specific purposes for which the PHI may be used.

We do not believe it is necessary to modify the Privacy Rules or add express regulatory permission for covered entities to disclose PHI to social service agencies or community-based support programs, because this is already permitted. The RFI states “[a]lthough the Privacy Rules permits a covered health care provider to disclose information to a third party for the coordination or management of treatment, some HIPAA covered entities have expressed reluctance to share this information for fear of violating HIPAA.” This speaks to a need for more training and technical assistance for providers, including those that are authorized to receive the relevant information but may be less familiar with the specifics of what the Rules provide and prohibit.

## **Question 22:**

Privacy and confidentiality are the touchstone of effective management and treatment for substance use disorders. Treatment for substance use disorder remains significantly different than many other areas of medical treatment because of the legal ramifications associated with disclosure of substance use disorders including loss of employment, loss of housing, loss of child custody, loss of benefits, discrimination by medical professionals, and arrest, prosecution, and incarceration.<sup>2</sup> The person receiving services should be at the center of their care, including directing and managing their own care and treatment. At the discretion of the person receiving care or services, caregivers should be involved and incorporated into treatment planning for substance use disorders. Such individuals may be reluctant to share relevant information about

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<sup>1</sup> Forrester Research for the California HealthCare Foundation, National Consumer Health Privacy Survey (CHCF 2005 Survey) 2005.

<sup>2</sup> <https://www.healthaffairs.org/doi/10.1377/hblog20170413.059618/full/> .

substance use with providers or seek treatment if they are not assured of confidentiality. OCR should focus instead on better engagement and education to clarify to people receiving services, providers, and caregivers how information can currently be shared and accessed to allow for better care coordination and caregiver involvement for people with substance use disorders.

**Question 23:**

We fully support care coordination, team-based care, and caregiver involvement, based on the informed consent of the person. Research shows that at least 8.4 million Americans provide care to an adult with an emotional or mental health needs and that these caregivers face complex, high-burden care situations, resulting in higher caregiver stress.<sup>3</sup> As OCR has already stated in guidance, the Privacy Rules allow for routine communication between health care providers and family caregivers.<sup>4</sup> When a person with a “serious mental illness” is present, health care providers may communicate with the person’s family members, friends, or other individuals involved in their care (or payment for care), so long as the person does not object. (See 45 CFR § 164.510(b)). OCR should consider better engagement and education to clarify for people with SMI, providers, and caregivers how information can be currently be shared and accessed to allow for better care coordination and caregiver involvement for people with SMI when that is consistent with the individual’s wishes.

**Question 25:**

CPR supports policies that prioritize the values of person-centered decision-making, self-determination, and informed consent for all individuals, including minors. We recommend centering information-sharing through consent, including maintaining the current standards for minors in the Privacy Rules in recognition of their unique privacy, confidentiality, and security needs.

We urge OCR to further educate and clarify for health care providers that HIPAA allows them to share or discuss an individual’s health information with their family, friends or others involved in their care or payment for care, as long as the individual does not object. It is also important to clarify that providers may tell the individual that they plan to discuss the information and give the individual an opportunity to object, or may decide, using their professional judgement, that the individual does not object.<sup>5</sup> We also know that an individual can consent to sharing their health information with family, friends, or others. Given the flexibility already included in existing regulations and guidance, we believe no further changes are necessary, though continued education on these issues would be beneficial.

Additional education and outreach efforts to health care providers would help remove HIPAA as a perceived barrier to appropriate sharing of health information with family caregivers when that

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<sup>3</sup> [https://www.caregiving.org/wp-content/uploads/2016/02/NAC\\_Mental\\_Illness\\_Study\\_2016\\_FINAL\\_WEB.pdf](https://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf).

<sup>4</sup> <https://www.hhs.gov/sites/default/files/hipaa-privacy-rule-and-sharing-info-related-to-mental-health.pdf>.

<sup>5</sup> See, e.g., OCR, “When Health Care Providers May Communicate About You with Your Family, Friends, or Others Involved In Your Care,”

[https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/consumer\\_ffg.pdf](https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/consumer_ffg.pdf) (last visited Feb. 11, 2019).

is consistent with the individual's wishes. Clarity resulting from additional education and outreach could help improve care coordination and case management involving family caregivers and the provision of care.

We also understand that relationships with family members and caregivers can be extremely complex and varied. Indeed, the interests of a patient and caregiver may not always be aligned or in the best interest of the patient. A person's right to confidentiality is paramount, for example, in situations of current or potential elder abuse, intimate partner violence, or when individuals (including minors) are seeking sensitive health care services. In cases where the person has decision-making capacity, we strongly support – and believe that HIPAA protects – privacy and confidentiality above caregiver or family involvement.

Parents already have considerable access to the treatment records for their children, as parents or guardians are generally considered the minor's personal representative and can exercise the minor's rights with respect to protected health information. OCR should maintain the current limitations on parental access in the following circumstances: 1) when state or other law does not require the consent of a parent or other person before a minor can obtain a particular health care service; 2) when someone other than the parent is authorized by law to consent to a particular health services for a minor; 3) when a parent agrees to a confidential relationship between the minor and a health care provider; and 4) when a provider believes that a minor is subject to abuse, neglect or endangerment.

In addition, we strongly support OCR's overarching deference to other federal and state laws for safeguarding minors' privacy and confidentiality. If OCR changes the policy of deferring to state law, we believe that would create greater confusion about how and where the HIPAA Privacy Rules apply. According to a recent article in the American Medical Association Journal of Ethics, patients who have the greatest fear of breaches of confidentiality include “those seeking sensitive services such as reproductive and sexual health, mental health services, substance use treatment; adolescents; those affected by domestic or intimate partner violence; and those covered as dependents on a family member's health insurance policy.”<sup>6</sup> We strongly recommend that OCR maintain the current balance in generally allowing parents' access to minors' health information while also protecting minors' right to privacy in specific circumstances.

Robust confidentiality protections are critical for encouraging people to seek and stay in care. If minors know that a parent might be able to see their records, they are less likely to seek care in the first place. Research confirms that when adolescents perceive that health services are not confidential, they report that they are less likely to seek care, particularly for substance abuse and reproductive health care.<sup>7</sup> Additionally, if minors do seek care, studies suggest that a perceived

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<sup>6</sup> <https://journalofethics.ama-assn.org/article/privacy-protection-billing-and-health-insurancecommunications/2016-03>.

<sup>7</sup> Melissa Weddle and Patricia Kokotailo, “Confidentiality and Consent in Adolescent Substance Abuse: An Update,” 7 Virtual Mentor, ETHICS JOURNAL OF THE AMA (March 2005).

increase in the risk of breach of confidentiality makes them less willing to disclose information necessary to mental health and substance abuse treatment.<sup>8</sup>

Changes to the Privacy Rules could worsen outcomes for children in abusive households. For example, some parents do not want to allow children to seek treatment for mental health conditions. While many minors will consent to involving their friends and family, young people for whom it may be unsafe to involve parents need a supportive and confidential patient-doctor relationship to achieve optimal health outcomes. The Privacy Rules allow a provider to deny a parent access to a minor's PHI if abuse or neglect is suspected; however, these provisions are not sufficient to safeguard against abuse.<sup>9</sup> If an abused minor knows that any care they seek could be disclosed to their abuser, regardless of potential exceptions, they may refuse to seek care and decline care when offered. We therefore do not support changes to the Privacy Rules that make it easier for parents to obtain treatment information for their minor children.

The existing Rules permit providers to share treatment information with family in certain circumstances. For example, current law does not prohibit health care providers from sharing information with family, friends, or caregivers unless the minor patient specifically objects.<sup>10</sup> If the minor is not present or is incapacitated, providers may use "professional judgment" to disclose pertinent information to a relative or friend if they determine it to be "in the best interests of the individual."<sup>11</sup> However, the provider must only share information that the involved person needs to know about the patient's care or payment.<sup>12</sup> A provider may *not* disclose such information if the patient objects and is not incapacitated or it is not in the best interests of the individual. We believe that the current standard, which permits the clinician to substitute his or her judgement for that of the patient, is already too permissive and certainly should not be weakened.

We also oppose changes that would allow parents to have increased access to the treatment information of their adult children. The Privacy Rules already allow such access with permission of the individual or if the individual does not object. Likewise, we do not believe that OCR should make changes to the Privacy Rules to make it easier for spouses to obtain the treatment information of their partner. The limitations already in place are an important protection in the case of a spouse seeking sensitive health services and/or in cases of intimate partner violence. Maintaining confidentiality for survivors of intimate partner violence is paramount to preserving the safety, privacy, and trust of those seeking services.<sup>13</sup>

#### **Question 26:**

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<sup>8</sup> Petrila, *supra* note 43 citing: D.O. Taube and A Elwork, "Researching the Effects of Confidentiality law on Patients' Self-disclosures," 21 PROFESSIONAL PSYCHOLOGY: RESEARCH AND PRACTICE, 72-75 (1990); Howard Roback and Mary Shelton, "Effects of Confidentiality Limitations on the Psychotherapeutic Process," 4 JOURNAL OF PSYCHOTHERAPY PRACTICE AND RESEARCH, 185-193 (1995).

<sup>9</sup> 45 CFR §§ 164.502(g)(5), 164.524(a)(3)(iii).

<sup>10</sup> *Id.* § 164.510(b)(2).

<sup>11</sup> *Id.* § 164.510(b)(3).

<sup>12</sup> *Id.*

<sup>13</sup> <https://www.techsafety.org/confidentiality/>.

Generally speaking, HIPAA establishes a federal floor of safeguards to protect the privacy of PHI. While HIPAA overrides any “contrary” state law, it has never preempted a state privacy law that is more stringent than HIPAA.<sup>14</sup> A more stringent state law is one that, among other things, prohibits or restricts a use or disclosure that would be permitted under HIPAA, gives an individual greater rights to access his or her own health records, or provides greater privacy protection for the individual who is the subject of the protected information.<sup>15</sup> Specifically for substance use disorder, most state laws require confidentiality protections that are stronger than HIPAA.<sup>16</sup> In addition, many states have laws that provide heightened confidentiality protections for HIV-related information, mental health records, reproductive health records, sexual violence-related records, and more.<sup>17</sup>

CPR strongly supports continuing to defer to state laws that require stricter privacy, confidentiality, and security requirements than HIPAA, including requirements around minor consent and personal representation. That is, if a state has a law allowing the minor to consent to treatment, then a parent should not be the personal representative of the minor with respect to information connected with that treatment and therefore, would not have right of access to the data under HIPAA. For decades, adolescents and the providers who care for them have expected that state standards of confidentiality will govern their care. Multiple states have relied on this expectation when adopting laws that explicitly give minors authority over their own information and records when they have the legal right to consent to care.<sup>18</sup> This is particularly salient for married minors, pregnant minors, emancipated minors, and minors seeking sensitive health services. Any changes to the current deference to state law and provider discretion would create a massive federal overreach into state health laws and impose a new federal viewpoint on states that have already decided these issues.

We also note that nothing in the current Privacy Rules gives spouses rights with respect to their spouse’s PHI unless that person consents. We believe that curbing interpersonal violence (IPV) is an important component of the Privacy Rules. Creating spousal rights to PHI will greatly impact whether a person experiencing IPV chooses to seek care, and we urge restraint in implementing any policy that jeopardizes patient health and safety.

We oppose any change that would eliminate deference to state laws that are more protective than HIPAA, as this would represent an unprecedented overreach by the federal government and will significantly weaken state privacy protections. We stress the importance of protecting HIPAA’s original intent by making sure that people remain at the center of their care at all times, continue to have the final say with respect to sharing of their PHI and have access to their records in an accessible format and in a timely manner.

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<sup>14</sup> 45 CFR §§ 160.202–203.

<sup>15</sup> *Id.* § 160.202.

<sup>16</sup> HEALTH INFORMATION & THE LAW, Disclosure of Substance Abuse Records Without Patient Consent: 50 State Comparison (Oct. 24, 2013), <http://www.healthinfoweb.org/comparative-analysis/disclosure-substance-abuserecords-without-patient-consent-50-state-comparison> [https://perma.cc/SMM3-KKAQ];

<sup>17</sup> See Joy Pritts et al., *The State of Health Privacy*, INSTITUTE FOR HEALTH CARE RESEARCH & POLICY (2d ed. 2002).

<sup>18</sup> English A and Kenney KE, *State Minor Consent Laws: A Summary*, second ed., Chapel Hill, NC: Center for Adolescent Health & the Law, 2003.

We understand the importance of information sharing among providers and other covered entities, particularly as a way to improve care. However, we strongly believe that HIPAA's Privacy Rules already allow for sufficient sharing of information between covered entities. For that reason, and as explained in our comments, we believe barriers to information and sharing under HIPAA are mostly perceived barriers that may be overcome by educating providers and other covered entities about when providers are allowed to, and in fact should engage in, information sharing.

If you have any questions about our comments, or would like further discussion, please contact Alison Barkoff at [abarkoff@cpr-us.org](mailto:abarkoff@cpr-us.org) or Molly Burgdorf at [mburgdorf@cpr-us.org](mailto:mburgdorf@cpr-us.org).

Sincerely,

/s/

Alison Barkoff  
Director of Advocacy