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February 12, 2019

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

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

Dear Director Severino,

Thank you for the opportunity to comment on the Office for Civil Rights' (OCR) Request for Information on Modifying HIPAA Rules to Improve Coordinated Care.<sup>1</sup> The National Health Law Program (NHeLP) protects and advances the health rights of low income and underserved individuals, families, and communities. NHeLP advocates, educates and litigates at the federal and state level.

We respond below to the questions set forth in the RFI for which NHeLP possesses considerable expertise. Since 1969, NHeLP has been a leader in fighting for access to care for low income people and has worked at the federal and state level to better serve the unique health care needs of underserved communities. By virtue of our role as patient and consumer advocates and as experts in health care law and policy, we are particularly aware of the importance of protecting the confidentiality of individuals' health information and of the need to ensure that patients maintain autonomy with respect to their care. Moreover, because of our work as advocates for populations who have been traditionally

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<sup>1</sup> Request for Information on Modifying HIPAA Rules To Improve Coordinated Care, 83 Fed. Reg. 64302 (Dec. 14, 2018), available at <https://www.federalregister.gov/documents/2018/12/14/2018-27162/request-for-information-on-modifying-hipaa-rules-to-improve-coordinated-care>.

neglected and discriminated against in our health care system, such as people of color, LGBTQ individuals, individuals with disabilities, individuals with HIV, and people with mental health conditions and/or substance use disorders (SUD), we are mindful of the disastrous consequences that removing or weakening privacy protection would have on access to care for these populations.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) authorized the Department of Health and Human Services to regulate the privacy and security of patient information.<sup>2</sup> The Privacy Rule and its protection of health information are critical. The protections against disclosure of health information helps people feel comfortable in accessing health care with the understanding that sensitive information will not be disclosed to entities or individuals that the person would not want to access to that information. At the same time, the Rule protects individuals' right to receive their own health information.

In a time where technology is playing an increasing role in health and health information, OCR should both keep up with technology and ensure protections are keeping pace as well. While we recognize OCR may wish to update the Rule to provide for easier and faster access for individuals to their PHI and to decrease the burden on individuals who choose to share their PHI with other health providers, OCR must prioritize protecting individual choice and understanding regarding who has access to their PHI in any changes it may propose to the Rule. These federal protections help ensure that individuals can establish a trusting relationship with their providers and feel safe seeking care. We urge OCR to continue these federal protections, and enhance them in places, so that individuals are able to maintain their dignity and autonomy within the health care system.

## **I. TIMELY RESPONSE TO INDIVIDUALS' REQUESTS FOR ACCESS TO PROTECTED HEALTH INFORMATION**

OCR seeks comments on whether situations exist that warrant requiring covered entities to respond to individuals' requests for a copy of their PHI in less than 30 days. Under current HIPAA regulations, covered entities must provide access to or copies of requested PHI no later than 30 calendar days after the request is received, regardless of the format in which the information is maintained and regardless of whether the information is maintained by a covered entity or by a business associate of the covered entity.<sup>3</sup> If a covered entity is

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<sup>2</sup> Pub. L. 104-191.

<sup>3</sup> *Id.* § 164.524(b)(2).



unable to meet this deadline, the Rule allows entities to extend the deadline by no more than an additional 30 days.<sup>4</sup>

**NHeLP strongly supports enhancing the requirement that covered entities respond to individuals' request to access information in a timely manner by shortening the timeframe from 30 days to 15 days for PHI maintained in non-electronic formats and close to real-time for PHI maintained in electronic format.** This timeliness requirement ensures that individuals retain the right to access their own PHI when needed and for the use intended by the individuals. For example, a patient who needs immediate care from a particular specialist or who seeks a second opinion from a different health care provider may wish to access her PHI in order to accurately convey the information to the new provider. This is particularly true when information is not transferred between health care providers even in situations where the Privacy Rule allows for such disclosures.

We recognize that technological advances have made it easier for covered entities to respond to PHI requests in a timely manner, particularly when the information is contained in electronic format. As of 2014, approximately two thirds of all medical providers were storing PHI in electronic format.<sup>5</sup> Information maintained in this format is easily accessible by covered entities and should be made available to individuals in a shorter timeframe than information maintained in other formats. For that reason, NHeLP supports requiring covered entities to provide copies of PHI maintained in an electronic record more rapidly than records maintained in other media. When information is available in electronic format, copies should be provided close to real-time.

**We also take this opportunity to encourage OCR to establish a new requirement for covered entities to provide PHI in accessible formats.** The Privacy Rule requires covered entities to provide copies of requested PHI in the form and format requested, if readily available, or in a readable hard copy form or other form and format as agreed to by the covered entity and the individual.<sup>6</sup> However, the Rule includes no accessibility standards and/or requirements attached to covered entities' obligation to respond to PHI requests in a timely manner. OCR has already implemented accessibility requirements in other areas of privacy. Consistent with Section 1557 of the ACA, for example, HHS has stated that the Privacy Rule requires covered entities to provide Notices of Privacy Practices that include "a clear, user friendly explanation of individuals rights with respect to

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<sup>4</sup> *Id.*

<sup>5</sup> Office of the National Coordinator for Health Information Technology, *Any, Certified, and Basic: Quantifying Physician EHR Adoption through 2014*, ONC Data Brief No. 28, September 2015, available at [https://www.healthit.gov/sites/default/files/briefs/oncdatabrief28\\_certified\\_vs\\_basic.pdf](https://www.healthit.gov/sites/default/files/briefs/oncdatabrief28_certified_vs_basic.pdf).

<sup>6</sup> 45 C.F.R. § 164.524(c)(2)(i).



their personal health information...”<sup>7</sup> As a result, it is widely understood that covered entities must make HIPAA forms available in multiple accessible formats and many entities offer forms in braille, large print, and audio, and in multiple languages for individuals with limited English proficiency.

Accessibility is equally important when responding to PHI requests. Lack of an accessibility requirement has made HIPAA’s right to access superfluous for many individuals who are unable to understand their own PHI, including people with disabilities and individuals with limited English proficiency. In addition, some entities provide access to PHI through web portals, yet these portals are not always fully accessible. Requiring covered entities to provide copies of PHI in accessible formats would ensure that all persons, regardless of disability status and English proficiency, have meaningful access to their PHI. Moreover, this accessibility requirement should extend to summaries provided by covered entities in lieu of PHI. Pursuant to the Privacy Rule, covered entities may provide a summary of PHI, instead of copies of all designated record sets.<sup>8</sup> While we support continuing this option, provided the individual consents, we ask OCR to consider adopting a requirement that any such PHI summaries be provided in a format that is accessible for individuals with disabilities and with limited English proficiency.

## **II. POTENTIAL NEW REQUIREMENT TO DISCLOSE INFORMATION**

OCR seeks comments on whether covered entities should be required to disclose PHI when requested by another covered entity for treatment purposes, and whether the requirement should extend to disclosures made for payment and/or health care operations purposes generally, or, alternatively, only for specific payment or health care operations purposes.

**NHeLP does not support any changes to 45 C.F.R. § 164.506 or other provisions that 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.**

**NHeLP supports 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**

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<sup>7</sup> HHS, *Model Notices of Privacy Practices*, <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/model-notices-privacy-practices/index.html>.

<sup>8</sup> 45 C.F.R. § 164.524(c)(2)(iii).



**that patient's treatment, and where the patient has been given the opportunity to limit the request to specific PHI or timeframes.** If this modification is adopted, we would further support a narrow definition of treatment activities in order to not undermine the purpose and function of the Privacy Rule.

Such a requirement to support treatment may improve care coordination and case management where, for example, a patient is receiving care from multiple health care providers in different health systems that do not share health data electronically, or where a patient has switched health care providers and seeks her treatment records from her previous provider. Under the current Rule, 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 is required to provide the information, has explicitly consented to the request for PHI, and has been allowed to limit the request to specific PHI or timeframes. 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.

**NHeLP 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.** NHeLP strongly opposes the provision of PHI to any non-covered entity for any purpose other than treatment of the person whose PHI is requested. Further, we strongly oppose any changes that could be construed to change the nature of HIPAA protections from establishing minimum requirements to establishing maximum requirements.

### **III. MINIMUM NECESSARY STANDARD**

OCR seeks comments on whether it should expand the exceptions to the minimum necessary standard. The minimum necessary standard, a key protection of HIPAA's Privacy Rule, requires covered entities and business associates to take reasonable efforts to limit the release of PHI to the minimum necessary to accomplish the intended purpose of the request.<sup>9</sup> This standard already excepts use or disclosures made for treatment

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<sup>9</sup> *Id.* §§ 164.502(b), 164.514(d).



purposes, pursuant to an individual's authorization, and disclosures to the individual who is the subject of the information.<sup>10</sup>

**NHeLP does not support expanding the exceptions to the minimum necessary standard.** Robust evidence demonstrates that patients will be less forthcoming were this privacy protection weakened.<sup>11</sup> If patients are afraid that their PHI will be used to criminally investigate or prosecute them, deny them insurance or a job, or be used against them in a divorce or child custody proceeding, then they will understandably not seek medical care or enter treatment in the first place. The minimum necessary standard, on the other hand, encourages individuals to seek care and build trust with their health care providers by assuring them that their information will not be disclosed unnecessarily. By encouraging people to seek care and enter and remain in treatment, which in turn makes it more likely they will manage and survive their health conditions, the minimum necessary standard improves patient care and outcomes.

The minimum necessary standard is also crucial because there is a history of disclosures leading to discrimination and stigma. For example, a school may seek information on a child's immunizations. If the provider sent the child's entire medical record, rather than the minimum necessary PHI, this could include sensitive information such as HIV status or other diagnosed conditions. Without the minimum necessary rule, the school may become aware of her HIV status and could subject the child to discriminatory practices that may affect the child's academic progress and social interactions.

Similarly, unnecessary disclosure of information related to a person's mental health diagnosis, SUD, or other condition might impact their employment, housing, relationships, or other life areas. Not all health information is stigmatizing, but may still affect how other people interact with an individual or assumptions that are made. This can have detrimental impact on people, not only in whether they are hired or promoted, are accepted to or evicted from housing, or generally have their communities treat them differently because of knowledge about their condition. As health care changes to become more focused on care coordination, social determinants of health, and other factors, the definition of health and what is considered health information might become less distinct for some. However, privacy of health information must remain a high priority.

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<sup>10</sup> *Id.*

<sup>11</sup> See, e.g., Israel T. Agaku et al., *Concern about Security and Privacy, and Perceived Control over Collection and Use of Health Information Are Related to Withholding of Health Information from Healthcare Providers*, 21 JOURNAL OF THE AMERICAN MEDICAL INFORMATICS ASSOCIATION 374-78 (2014); Sarah C.M. Roberts & Amani Nuru-Jeter, *Women's Perspectives on Screening for Alcohol and Drug Use in Prenatal Care*, 20 WOMEN'S HEALTH ISSUES 193 (May 2010), <https://www.ncbi.nlm.nih.gov/pubmed/20457407>.



For example, just because housing has been identified as a need to promote an individual's health does not mean that everyone involved in trying to find a person a place to live needs to know everything about their condition. The rental agency or community group helping to find housing does not need to know about a health condition unless the person needs accommodations in their housing. If that type of information is shared to non-HIPAA covered entities, it would allow the important protections to be undermined simply because something is related to health. This could mean that a person's information is suddenly known more broadly than necessary and not protected in the same way. This is particularly relevant in smaller or more tight knit communities. While the team involved an issue related to health may be broader than the health care providers, health information must continue to be shared on a "need to know basis" set at a very high bar and continue to be protected within that circle of providers or individuals.

Moreover, particularly for communities of color, PHI has historically been used against individuals to take away their children, housing, or economic opportunity, just as often as it has been used to enhance care. For example, enrollment in Medicaid may be used to presume that children, by virtue of living in poverty, are being subject to abusive or unhealthy environments, which may give way to unfounded investigations by Child Protective Services agencies.<sup>12</sup> This is particularly troublesome for people of color, who studies demonstrate show the greatest concern about the privacy of their medical records.<sup>13</sup> Therefore, NHeLP 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.

#### **IV. DISCLOSURE OF INFORMATION TO NON-COVERED ENTITIES**

OCR seeks comment on changes and clarifications to the Privacy Rule regarding the ability of covered entities' ability to disclose PHI to social service agencies and community-based support programs where necessary to facilitate treatment and coordination of care with the provision of other services to the individual.

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<sup>12</sup> Gellman, B. & Adler-Bell, Sam, *The Disparate Impact of Surveillance*, The Century Foundation (Dec. 21, 2017), <https://tcf.org/content/report/disperate-impact-surveillance/?session=1>; See also Bridges, K.M., Privacy Rights and Public Families, 34 HARVARD JOURNAL OF LAW AND GENDER 113 (2011), [https://papers.ssrn.com/sol3/papers.cfm?abstract\\_id=1926757](https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1926757).

<sup>13</sup> Forrester Research for the California HealthCare Foundation, National Consumer Health Privacy Survey (CHCF 2005 Survey) 2005.



**While NHeLP understands and appreciates the increasingly interdisciplinary nature of care delivery, NHeLP opposes any changes that would permit additional disclosure of covered PHI to any non-covered entities.** The current Rule permits disclosure of PHI a) for the purposes of treatment; or b) 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. OCR could clarify that these existing permissions can be used to make disclosures to social service agencies and community-based support programs. Since these entities may already be providing services to the individuals, we expect that, in most situations, it will be easy for health care providers to obtain consent from the individuals before disclosing PHI. Finally, regardless of which proposal OCR adopts, we believe it is important to make clear that, in all situations, disclosure to non-covered entities remains governed by the minimum necessary standard.

## **V. EDUCATIONAL ACTIVITIES**

OCR seeks comment on whether increased public outreach and education on existing HIPAA provisions that permit use and disclosures of PHI would be sufficient to effectively facilitate care coordination and case management.

**NHeLP strongly supports additional education because we feel the largest barriers under HIPAA are perceived rather than *de jure*.** We suggest the following areas for sub-regulatory guidance:

- Fact sheet on how HIPAA promotes person-centered care;
- FAQ on care coordination and social determinants of health, including a list of social determinants of health services that might benefit from access to PHI (housing, meal delivery services, school-based health care) and the privacy standards required;
- List of existing HIPAA provisions that allow for information sharing in certain situations and the appropriate documentation;
- Model releases and patient notices;
- Template data use agreements for disclosing limited data sets;
- Best practices for covered entity-to-covered entity sharing as well as covered entity-to-non-covered entity.
- Fact sheet on how HIPAA rules can be used to advanced care coordination and improve communication between providers; and
- FAQ on the situations when it is necessary to obtain patient consent and when providers may obtain limited consent.



In addition to these materials, we recommend that OCR develop an educational campaign targeted at health care providers and other covered entities with the purpose of clarifying areas in which the Privacy Rule allows them to freely engage in information sharing. This campaign could also encourage providers to work through the Privacy Rule to improve communication with other providers and care coordination. OCR could even set up a direct phone line or email where providers may submit questions about situations governed by the Privacy Rule. The main goal of this campaign should be to dispel with the perceived barriers that some providers believe HIPAA creates and to create a system in which covered entities feel free to work in ways that improve care coordination while maintaining HIPAA confidentiality protections.<sup>14</sup>

NHeLP believes these educational materials can help address perceived barriers to data sharing for a number of groups, particularly patients, caregivers, providers, clinical staff and administrators, professional associations, managed care plans, case managers, and care coordination entities.

## **VI. INTERPLAY BETWEEN HIPAA AND MENTAL HEALTH AND OPIOID USE DISORDERS**

OCR seeks comment on whether changes to the Privacy Rule could help ensure that parents are able to obtain the treatment information of their minor children, and what limitations on parental access should apply. NHeLP 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 patient consent, and maintaining the current standards for minors in the Privacy Rule in recognition of their unique privacy, confidentiality, and security needs.**

Robust confidentiality protections are critical for encouraging minor patients 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 SUDs and reproductive health care.<sup>15</sup> Additionally, if minors do seek care,

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<sup>14</sup> See, e.g., SAMHSA-HRSA Center for Integrated Care Solutions: Confidentiality, <https://www.integration.samhsa.gov/operations-administration/confidentiality> (setting forth resources to help providers understand confidentiality, integrated care, and how to overcome perceived privacy obstacles, including a contact number for questions).

<sup>15</sup> Melissa Weddle & Patricia Kokotailo, *Confidentiality and Consent in Adolescent Substance Abuse: An Update*, 7 Virtual Mentor, ETHICS JOURNAL OF THE AMA (March 2005).



studies suggest that a perceived increase in the risk of breach of confidentiality makes them less willing to disclose information necessary to mental health and SUD treatment.<sup>16</sup>

In particular, changes to the Privacy Rule allowing greater disclosure to parents 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 in treatment, and health care professionals encourage and help them to do so when appropriate, young people for whom it may be unsafe to involve parents need a supportive and confidential patient-provider relationship to achieve optimal health outcomes. The Privacy Rule does 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>17</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 Rule that make it easier for parents to obtain treatment information for their minor children.

The existing Rule permits 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 patient, including a minor patient who is considered 'an individual,' specifically objects.<sup>18</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>19</sup> However, the provider must only share information that the involved person needs to know about the patient's care or payment.<sup>20</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, if anything, too permissive.

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<sup>16</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 & Mary Shelton, *Effects of Confidentiality Limitations on the Psychotherapeutic Process*, 4 JOURNAL OF PSYCHOTHERAPY PRACTICE AND RESEARCH, 185-193 (1995); Ford CA, Millstein SG, Halpern-Felsher BL, Irwin CE, *Influence of Physician Confidentiality Assurances on Adolescents' Willingness to Disclose Information and Seek Future Health Care: A Randomized Controlled Trial*, JAMA. 1997;278(12):1029-1034.

doi:10.1001/jama.1997.03550120089044

<sup>17</sup> 45 C.F.R. §§ 164.502(g)(5), 164.524(a)(3)(iii).

<sup>18</sup> *Id.* § 164.510(b)(2).

<sup>19</sup> *Id.* § 164.510(b)(3).

<sup>20</sup> *Id.*



There are other situations in which HIPAA rules are sufficient for providers to obtain necessary information. For instance, the Privacy Rule does not prevent a provider from entering relevant information given by a family member into the patient medical record, even if the patient does not consent to giving this information. For example, an emergency provider department could ask an incoherent patient's family members if they are aware of any specific drugs that patient might have taken in order to initiate the most appropriate treatment.

The current HIPAA regulations also create an exemption to avert a serious threat to health or safety.<sup>21</sup> Under that exemption, a covered entity may disclose PHI if it is necessary to prevent or lessen a serious threat to the health or safety of a person, and the disclosure is to a person reasonably able to prevent or lessen the threat.<sup>22</sup> For example, current Department of Health and Human Services guidance instructs that "a doctor whose patient has overdosed on opioids is presumed to have complied with HIPAA if the doctor informs family, friends, or caregivers of the opioid abuse after determining, based on the facts and circumstances, that the patient poses a serious and imminent threat to her health through continued opioid abuse upon discharge."<sup>23</sup>

NHeLP has concerns that this existing guidance is not in keeping with the language or goals of the Privacy Rule. Addiction is a chronic, relapsing disease, and, in the case of patients with opioid use disorders, it is not unreasonable to think that most will continue to misuse opioids upon discharge. This reading, therefore, appears to permit a health care provider to inform friends and family members that a patient has overdosed even without that patient's consent. We do not believe that this is an appropriate reading of the Rule and do not believe that modifications that would expand the existing standard to allow and/or encourage the release of PHI without the patient's knowledge or over her objection are necessary or advisable.

OCR also seeks comment on whether to continue deferring to state or other applicable law to determine the authority of a person to act as a personal representative of an individual in making decisions related to their health care, and how to reconcile changes to a personal representative under HIPAA with state laws that define the scope of parental or spousal authority for state law purposes. We have answered some of the specific questions OCR asked below.

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<sup>21</sup> *Id.* at § 164.512(j).

<sup>22</sup> *Id.*

<sup>23</sup> U.S. Dep't. of Health and Human Servs., Office for Civil Rights (OCR), *How HIPAA Allows Doctors to Respond to the Opioid Crisis* (Oct. 27, 2017), <https://www.hhs.gov/sites/default/files/hipaa-opioid-crisis.pdf>.



## **General Comments on State Laws**

Generally, 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>24</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 her own health records, or provides greater privacy protection for the individual who is the subject of the protected information.<sup>25</sup> Specifically for SUD, most state laws require confidentiality protections that are stronger than HIPAA.<sup>26</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>27</sup>

**NHeLP strongly supports continuing to allow states to have laws that require stricter privacy, confidentiality, and security requirements than HIPAA and continuing to defer to states for requirements around minor consent and personal representation. That is, if a state has a law allowing the minor to consent to health care and protects the confidentiality of information about the care, then a parent should not be the personal representative of the minor with respect to information connected with that treatment and would not have right of access to the data under HIPAA.**

## **Minors’ Records**

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>28</sup> This is particularly salient for married minors, pregnant minors, emancipated minors, and minors seeking sensitive health services. **Any changes that would override state law and**

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<sup>24</sup> 45 C.F.R. §§ 160.202–203.

<sup>25</sup> *Id.* § 160.202.

<sup>26</sup> Health Information & the Law, *Disclosure of Substance Abuse Records Without Patient Consent: 50 State Comparison* (Oct. 24, 2013), <http://www.healthinfo.org/comparative-analysis/disclosure-substance-abuse-records-without-patient-consent-50-state-comparison> [https://perma.cc/SMM3-KKAQ].

<sup>27</sup> See Joy Pritts et al., *The State of Health Privacy*, INSTITUTE FOR HEALTH CARE RESEARCH & POLICY (2d ed. 2002).

<sup>28</sup> English A & Kenney KE, *State Minor Consent Laws: A Summary*, second ed., Chapel Hill, NC: Center for Adolescent Health & the Law, 2003.



**eliminate or weaken 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.**

### ***Spousal Records***

We also note that nothing in the current Privacy Rule gives spouses rights with respect to their spouse's PHI unless that person consents. **We support HHS' dedication to promoting healthy relationships, including but not limited to marital relationships, and believe that curbing interpersonal violence (IPV) is an important component of the Privacy Rule.** Creating spousal rights to PHI will greatly impact whether a person experiencing IPV chooses to seek care and the person's willingness to convey necessary information to health care providers. For example, someone experiencing IPV may seek out mental health care in response to their abuse, but may not initially disclose all of the information that would warrant an exception to HIPAA under 45 CFR § 502(g)(5) or 45 CFR § 512(c). If an abusive spouse were able to access information showing that the person experiencing IPV sought treatment without the abuser's knowledge or permission, it exposes the patient to physical, emotional, and/or financial abuse. Given these concerns, we would oppose any policy that jeopardizes patient health and safety in this area.

Similarly, we do not believe that an individual loses their interest in PHI as they age or have chronic health conditions that may require them to need additional assistance from caregivers. Not all individuals whom family or other caregivers may seek information about or otherwise attempt to become part of health treatment want those individuals to have knowledge regarding their health or be involved. **In order to promote self-determination and individual rights, PHI must continue to be protected and not disclosed without the individual's consent.**

## **VII. CONCLUSION**

While NHeLP supports efforts to facilitate communication between providers and improve care coordination and integration, we strongly believe those actions should not come at the expense of protecting patient confidentiality. OCR should consider the impact that proposals to modify HIPAA would have on patient privacy before adopting any changes. For example, we oppose any changes to the Privacy Rule's minimum necessary standard and expanding the exceptions to the standard because it will disrupt patients' willingness to share information, including information essential to the course of treatment, with providers. Similarly, we oppose any change that seeks to override state laws that are more protective than HIPAA, including eliminating the current deference standard around minors' personal



representatives, as this would represent an unprecedented overreach by the federal government and significantly weaken state privacy protections. We stress the importance of protecting HIPAA's original intent by making sure that patients remain at the center of their care at all times. Patients must continue to have the final say with respect to sharing of their PHI and must have access to their records in an accessible format and in a timely manner.

We understand the importance of information sharing among providers and other covered entities, particularly as a way to improve patient care. Care coordination, care planning, integrated care, and other care models that require information sharing are supposed to be person-centered and require a level of trust or cooperation from the individual, which would be unlikely if PHI was not well protected.<sup>29</sup> We strongly believe that HIPAA's Privacy Rule already allows 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.

We acknowledge however, that even with better education, covered entities and providers may still refuse to disclose information even when allowed by the Privacy Rule. For that reason, we have recommended throughout our comments limited changes to the Privacy Rule that would expand information sharing. As explained above, for example, we would support a requirement that covered entities disclose information for treatment purposes to another covered health care provider that requests the information where the patient has been given the opportunity to limit the request to specific PHI or timeframes and has explicitly consented to the disclosure. In addition, while we generally oppose allowing covered entities to disclose PHI to non-covered entities, we favor continuing and educating providers about permissible disclosures of this type when done for treatment purposes and with the patient's explicit consent, and would strongly support clarification about situations when PHI may be disclosed to social agencies and community-based support programs.

We believe these limited modifications are sufficient to ease the current, mostly perceived, barriers to care coordination under HIPAA while protecting confidentiality and ensuring patient autonomy.

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<sup>29</sup> See Elizabeth Edwards, National Health Law Program, *Assessing Changes to Medicaid Managed Care Regulations: Facilitating Integration of Physical and Behavioral Health Care* (Oct. 24, 2017), <https://www.commonwealthfund.org/publications/issue-briefs/2017/oct/assessing-changes-medicaid-managed-care-regulations-facilitating> (discussing the need for individual trust and interaction with a care team as part of successful integrated care models).



If you have any questions about our comments, please contact Héctor Hernández-Delgado ([hernandez-delgado@healthlaw.org](mailto:hernandez-delgado@healthlaw.org) or 213-378-2678).

Sincerely,

A handwritten signature in black ink that reads "Elizabeth G. Taylor". The signature is written in a cursive, flowing style.

Elizabeth G. Taylor  
Executive Director

