



February 8, 2019

Alex M. Azar II  
Secretary  
U.S. Department of Health and Human Services  
200 Independence Avenue, S.W.  
Washington, D.C. 20201  
Submitted electronically to <http://www.regulations.gov>

**Re: HHS-OCR-0945-AA00; Request for Information on Modifying HIPAA Rules to Improve Coordinated Care**

Dear Secretary Azar:

Nemours Children's Health System (Nemours) appreciates the opportunity to provide comments on the Department of Health and Human Services (HHS), Office for Civil Rights (OCR) Request for Information (RFI) on modifying Health Insurance Portability and Accountability Act (HIPAA) rules to improve coordinated care.

Nemours is an internationally recognized children's health system that owns and operates the Nemours/Alfred I. duPont Hospital for Children in Wilmington, Del., and Nemours Children's Hospital in Orlando, Fla., along with outpatient facilities in six states, delivering pediatric primary, specialty, and urgent care to children from all 50 states. Established as The Nemours Foundation through the legacy and philanthropy of Alfred I. duPont, Nemours provides pediatric clinical care, research, education, advocacy, and prevention programs to families in the communities we serve.

In 2018, Nemours provided care to more than 400,000 children, from across the United States and more than 70 countries. Through Nemours CareConnect, patients are able to access board certified pediatricians and subspecialists for urgent care, patient visits, and follow up care. Nemours also powers the world's most-visited website for information on the health of children and teens, KidsHealth.org. We are committed to leveraging our experience on the ground to inform policies and practices nationally to benefit all children, not just those in the regions we serve. Our mission is to help all children grow up healthy and have the best chance for success in life.

**Summary**

Nemours is committed to providing the best possible care to our patients. This requires care coordination and information sharing among members of a patient's care team. We fully support existing HIPAA protections afforded to patients, and aim only to harmonize those protections with various other privacy laws in order to promote high quality patient care. In answering the questions below, we find that two key themes emerge:

1. Variation among state laws, as well as various federal laws such as HIPAA and the Family Educational Rights and Privacy Act (FERPA), regarding patient privacy and consent is a barrier to information exchange. As a result, providers working across multiple jurisdictions must comply with multiple, inconsistent sets of rules and regulations concerning patient privacy and consent, which is not only an administrative and legal burden, but a barrier to information sharing and, therefore, care coordination; and
2. Existing misalignment between various pediatric health, social service, and safety net programs across multiple local, state and federal organizations, authorized under multiple statutory, regulatory, and funding authorities do not incentivize organizations to work together to overcome existing challenges and barriers. In fact, this misalignment, particularly with regard to payment, may serve as a disincentive to effective care coordination and population-based case management activities.

### **Nemours recommends that HHS:**

1. Attempt to address the above barriers caused by the variation in consent policies across health information exchange (HIE) organizations by convening experts to make recommendations regarding what could be done to create a more consistent and harmonized compliance landscape.
2. In the absence of a consistent regulatory landscape across states, provide further guidance on the interdependencies across state and federal privacy regulations, such as a crosswalk of state and federal law governing the exchange of protected health information (PHI), which should also address the intersection of HIPAA, FERPA, and the various other federal laws and regulations that affect privacy.

Below are responses to specific questions posed by HHS in the RFI.

### **Promoting Information Sharing for Treatment and Care Coordination**

**Question #6:** Do health care providers currently face barriers or delays when attempting to obtain PHI from covered entities for treatment purposes? For example, do covered entities ever affirmatively refuse or otherwise fail to share PHI for treatment purposes, require the requesting provider to fill out paperwork not required by the HIPAA Rules to complete the disclosure (e.g., a form representing that the requester is a covered health care provider and is treating the individual about whom the request is made, etc.), or unreasonably delay sharing PHI for treatment purposes? Please provide examples of any common scenarios that may illustrate the problem.

Nemours' experience is that the primary barriers to obtaining PHI for treatment purposes are:

- The variation across many sets of rules and regulations to which a covered entity must comply, particularly as institutions like Nemours span multiple state borders; and
- A general misalignment of incentives that currently discourages information sharing.

HIPAA represents the easiest of these sets of rules to implement, partially because HIPAA rules are standard across all jurisdictions, and partially because they have been modified to reduce barriers and encourage appropriate exchange of PHI. However, because HIPAA is often treated as a “floor” for privacy regulation, state laws are often more stringent and variable. Our health system, like many others, operates across state lines, so meeting the privacy, consent, and other compliance requirements creates increased administrative and legal burden, which in turn does not effectively promote information sharing. This is particularly relevant for pediatric systems, facing more specific questions of consent, especially when we consider state laws governing adolescent privacy. This unique challenge should be addressed explicitly as it is an important transition in the continuum of care. We find these privacy requirements are particularly relevant in cases where children are wards of the state and have pieces of their health record in multiple places as they age.

In addition to regulatory barriers, in our experience there are instances in which other providers have chosen not to share PHI or intentionally delayed the sharing of PHI in order to protect their business and retain patients. In most cases, business, clinical and cultural practices are shaped by the regulatory environment. As a result, it is critical that the right regulatory incentives are in place at the state and federal level. As long as the fee-for-service model persists, the health care system may struggle to fully achieve robust and free-flowing information exchange because some may view it as more profitable to “hoard” clinical information and may resist efforts to reduce duplication of services.

**Question #7:** Should covered entities be required to disclose PHI when requested by another covered entity for treatment purposes? Should the requirement extend to disclosures made for payment and/or health care operations purposes generally, or, alternatively, only for specific payment or health care operations purposes?

Nemours believes that covered entities should be required to disclose PHI for treatment purposes unless there is a valid case for not doing so, which would likely be extraordinary and rare. However, PHI should not need to be shared for business operations.

**Question #9:** Currently, HIPAA covered entities are permitted, but not *required*, to disclose PHI to a health care provider who is not covered by HIPAA (*i.e.*, a health care provider that does not engage in electronic billing or other covered electronic transactions) for treatment and payment purposes of either the covered entity or the non-covered health care provider. Should a HIPAA covered entity be required to disclose PHI to a non-covered health care provider with respect to any of the matters discussed in Questions 7 and 8? Would such a requirement create any unintended adverse consequences? For example, would a covered entity receiving the request want or need to set up a new administrative process to confirm the identity of the requester? Do the risks associated with disclosing PHI to health care providers not subject to HIPAA’s privacy and security protections outweigh the benefit of sharing PHI among all of an individual’s health care providers?

Nemours is not aware of examples where a health care provider would not be a covered entity. The most relevant scenario, in our view, would be information exchange with a school health clinic. However, the challenge in this case is not the lack of a requirement for information disclosure under HIPAA, but rather the interplay between HIPAA and FERPA requirements, which both govern such data.

**Question #11:** Should OCR create exceptions or limitations to a requirement for covered entities to disclose PHI to other health care providers (or other covered entities) upon request? For example, should the requirement be limited to PHI in a designated record set? Should psychotherapy notes or other specific types of PHI (such as genetic information) be excluded from the disclosure requirement unless expressly authorized by the individual?

Nemours believes that the minimum necessary requirement is sufficient in most cases, but that OCR should create exceptions and/or limitations to a requirement for PHI disclosure for certain types of data under specific circumstances. In general, HIPAA should be more nuanced in order to be effective as a common standard, particularly when addressing adolescent health. More specifically, HIPAA should provide a consistent policy allowing an individual to place a sequester around certain sensitive information – such as mental health, substance abuse and sexual health data – and prevent disclosure to parents/guardians or non-covered entities without express consent by the individual.

The specific question about psychotherapy notes raises the need for continued discussion about mental health in the context of HIPAA. Part of this discussion should include a distinction between information relevant for treatment purpose and information that may be helpful but is not necessary. For example, sharing mental health notes with another health care provider will likely aid that provider in giving appropriate and effective care to a patient, considering that mental health and physical health are often closely linked. This type of information should be shared without additional protections or layers of consent, as it is critical in promoting the overall health of a patient. Conversely, psychotherapy notes are distinctly different from mental health notes and are not necessary in the course of providing of care, nor do they provide critical information that would not already exist in mental health notes. Therefore, existing protections and additional layers of consent for psychotherapy notes and other similar categories of information should be maintained.

**Question #13:** Should individuals have a right to prevent certain disclosures of PHI that otherwise would be required for disclosure? For example, should an individual be able to restrict or “opt out” of certain types of required disclosures, such as for health care operations? Should any conditions apply to limit an individual’s ability to opt out of required disclosures? For example, should a requirement to disclose PHI for treatment purposes override an individual’s request to restrict disclosures to which a covered entity previously agreed?

Individuals should have the right to place a sequester around certain types of sensitive information and disallow that information from being shared with non-covered entities and/or parents and guardians. This question again raises the need for HIPAA to address adolescent health and privacy in an explicit manner. There is a distinction between disclosing sensitive

information to a treating provider and disclosing that information to a parent or guardian. The rules surrounding each type of disclosure should be distinct as well.

**Question #16:** What considerations should OCR take into account to ensure that a potential Privacy Rule requirement to disclose PHI is consistent with rulemaking by the Office of the National Coordinator for Health Information Technology (ONC) to prohibit “information blocking,” as defined by the 21st Century Cures Act?

As stated previously, we believe that a barrier to information exchange is a misalignment of incentives. A fee-for-service payment model can dis-incentivize information sharing between providers. As long as providers are paid according to volume, sharing patients and reducing duplication will likely result in a reduction in revenue.

However, privacy policies governing information exchange in a value-based health care system should be nuanced, as discussed in previous questions, to ensure that information exchange is appropriate and centered on the best interest of the individual. The minimum necessary requirement may already address some of these concerns, but special attention and care should be paid to sensitive categories of PHI, especially for adolescents, to ensure that disclosures do not inadvertently harm the patient when information is shared with multi-disciplinary teams.

**Question #21:** Are there provisions of the HIPAA Rules that work well, generally or in specific circumstances, to facilitate care coordination and/or case management? If so, please provide information about how such provisions facilitate care coordination and/or case management. In addition, could the aspects of these provisions that facilitate such activities be applied to provisions that are not working as well?

HIPAA has been effective in promoting electronic exchange of records, and does not require additional consent exchange related to treatment and care coordination, which is extremely helpful. Challenges arise when organizations look to state laws that are more restrictive and therefore choose not to share records without consent. More consistency among state privacy laws would be very helpful. In the absence of consistent state laws, however, additional guidance from OCR providing a crosswalk of state and federal law interdependencies would be extremely helpful.

One area that could be improved is the intersection between HIPAA and FERPA, particularly in instances where health providers work with school health clinics to care for school-age children. The lack of alignment between these two federal laws can be a barrier to case management and care coordination. **Nemours recommends that PHI generated at a school health clinic be covered by HIPAA requirements, rather than by FERPA.** For example, patient information collected by a nurse in a school health clinic should be classified as health information and not educational information. In its current state, FERPA requirements are too restrictive to promote information exchange with health providers, and may not protect health information from being shared with non-health providers in a school system.



## Promoting Parental and Caregiver Involvement and Addressing the Opioid Crisis and Serious Mental Illness (SMI)

**Question #24:** Are there circumstances in which parents have been unable to gain access to their minor child's health information, especially where the child has substance use disorder (such as opioid use disorder) or mental health issues, because of HIPAA? Please specify, if known, how the inability to access a minor child's information was due to HIPAA, and not state or other law.

Nemours has not experienced circumstances in which parents or guardians have been unable to gain access to their minor child's health information due to HIPAA rules. However, Nemours is aware that state and federal regulations prohibit disclosures of certain categories of an adolescent patient's PHI without consent, such as mental health, substance use and sexual health information. This prohibition is appropriate and should remain in place.

**Question #25:** Could changes to the Privacy Rule help ensure that parents are able to obtain the treatment information of their minor children, especially where the child has substance use disorder (including opioid use disorder) or mental health issues, or are existing permissions adequate? If the Privacy Rule is modified, what limitations on parental access should apply to respect any privacy interests of the minor child?

Existing permissions appear to be adequate as they relate to parents' and caregivers' access to their minor children's treatment information, including cases when the child has been diagnosed with a substance use disorder or mental health disorder. However, the administrative and legal burden related to providers navigating multiple state laws adds a layer of complexity that often leads to confusion and impedes coordination of care.

**Question #25a:** Currently, the Privacy Rule generally defers to state law with respect to whether a parent or guardian is the personal representative of an unemancipated minor child and, thus, whether such parent or guardian could obtain PHI about the child as his/her personal representative; if someone other than the parent or guardian can or does provide consent for particular health care services, the parent or guardian is generally not the child's personal representative with respect to such health care services. Should these standards be reconsidered generally, or specifically where the child has substance use disorder or mental health issues?

This question raises unique considerations related to adolescent health that children's hospitals routinely navigate. The answer to this question is complex given the combination of federal and state laws and the necessity of health care providers to consider a matrix of clinical and legal issues. As previously stated, individuals should have the right to place a sequester around certain types of sensitive information and disallow that information from being shared with non-covered entities and/or parents and guardians.

**Question #25b:** Should any changes be made to specifically allow parents or spouses greater access to the treatment information of their children or spouses who have reached the age of majority? If the Privacy Rule is changed to encourage parental and spousal

involvement, what limitations should apply to respect the privacy interests of the individual receiving treatment?

Nemours does not endorse modifying HIPAA laws to allow for greater access to an adolescent's PHI when the child reaches the age of majority. Nemours supports how state laws and regulations currently safeguard an adolescent's health information with specific release restrictions and additional consent requirements that allow an adolescent patient to discern whether to disclose certain categories of PHI to a parent/guardian. One potential exception would be in cases of diminished capacity to consent, which may be an area for further discussion. It is important to be sensitive to the needs of our most vulnerable populations and for health care providers to assess a patient's ability to understand and weigh the risks and benefits related to informed consent.

Since HIPAA has deferred to the states on the issue of consent, significant variation of consent requirements across the states creates an administrative and legal burden for providers. **Nemours recommends that HHS convene experts to discuss the potential merits of creating a national approach to consent policy, or encouragement toward state alignment on consent policies for children who reach the age of majority.**

**Question #26:** The Privacy Rule currently defers to state or other applicable law to determine the authority of a person, such as a parent or spouse, to act as a personal representative of an individual in making decisions related to their health care. How should OCR reconcile any changes to a personal representative's authority under HIPAA with state laws that define the scope of parental or spousal authority for state law purposes?

If there was more consistency between federal and state laws, then there would not be a need to reconcile changes to a personal representative's authority under HIPAA with state laws. As noted above, Nemours suggests that HHS convene experts to further explore how greater consistency in privacy policy across states could be achieved.

### **Additional Recommendations to Further Reduce Burden and Promote Coordinated Care**

**Question #54a:** What provisions of the HIPAA Rules may present obstacles to, or place unnecessary burdens on, the ability of covered entities and/business associates to conduct care coordination and/or case management? What provisions of the HIPAA Rules may inhibit the transformation of the health care system to a value-based health care system?

Rather than modifying specific provisions of the HIPAA rules, we believe it would be more helpful to address the context in which HIPAA rules operate. For example, the fee-for-service payment model can promote a misalignment of incentives. Additionally, the complexity of the regulatory landscape places unnecessary burdens on providers in the course of treatment and care coordination.

# Nemours. Children's Health System

As the policy and payment landscape shifts, HIPAA regulations should be re-examined and refreshed to ensure that they are not inappropriately inhibiting cross-sector data sharing, while ensuring protections for patient privacy.

## **Conclusion**

Nemours sees great value in accelerating pediatric population health improvement and health system transformation. We are committed to both patient privacy and care coordination and see the value in both. We thank you for the opportunity to provide comments. Please do not hesitate to have your team reach out to Amber Hewitt, Manager of Policy & Advocacy at [amber.hewitt@nemours.org](mailto:amber.hewitt@nemours.org) with any questions or requests for additional information.

Sincerely,



Kevin D. Haynes  
Chief Privacy Officer  
Nemours Children's Health System