February 12, 2019

Roger Severino
U.S. Department of Health and Human Services
Director of the Office for Civil Rights
Attention: RFI, RIN 0945-AA00
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

Submitted Electronically via Regulations.Gov

Re: RIN 0945-AA00 or Docket HHS-OCR-0945-AA00

Dear Mr. Severino:

I am writing on behalf of the National Association of Health Underwriters (NAHU), a professional association representing more than 100,000 licensed health insurance agents, brokers, general agents, consultants, and employee benefit specialists. We are pleased to have the opportunity to provide comments in response to your request for information concerning modifying the Health Insurance Portability and Accountability Act (HIPAA) privacy and data security rules to improve coordinated care published in Volume 83, Number 240 of the Federal Register on December 14, 2018.

The members of NAHU are primarily state-licensed health insurance producers who work daily to help millions of individuals and employers purchase, administer and utilize health insurance coverage. Virtually all of our members, as well as their businesses or employers, qualify as either covered entities or business associates subject the HIPAA privacy regulations and the related Health Information Technology for Economic and Clinical Health Act (HITECH) data security rules. Furthermore, many of our members’ employer clients are operators of self-funded group health insurance plans, so they qualify as covered entities under these rules, and they rely on NAHU members for HIPAA and HITECH compliance assistance. Finally, NAHU agents and brokers work directly with individual purchasers of health insurance and routinely help individual beneficiaries with health insurance claims and payment issues, and HIPAA privacy concerns sometimes arise.

Given all of this direct exposure to the privacy rules, NAHU believes we have a great deal of real-life experience to share about how the current privacy requirements impact agents and brokers, group health insurance plans and consumers. Brokers who work directly on privacy compliance issues contributed their insights to help prepare this response. As requested, we have shared an overview of our viewpoint on the topic at hand, and have developed answers to specific questions delineated in the request for information.

**General Response to the Request for Information**

NAHU would like to commend the Trump Administration and the Department of Health and Human Services for issuing this request for information. It has been more than 15 years since the HIPAA privacy rules first went into effect, and the related HITECH data security rules have been in place for just under a decade. In that time,
healthcare and health insurance options have changed dramatically, new market-based payment strategies designed to reduce costs and improve patient care have been employed, and there have been significant public health changes, particularly regarding the need for more effective substance abuse and mental healthcare diagnoses and treatment. Beyond that, rapid technological and data-sharing advances mean that current privacy and data-security rules likely are insufficient when it comes to not only allowing for the best means of treating patients and financing their care but also in terms of adequately protecting the privacy of health information, so NAHU believes that your current inquiry is quite timely.

In the request-for-information document, you ask broadly for information about how the current HIPAA regulatory framework is affecting the ability of covered entities and business associates to transform the healthcare system and provide vital functions such as care coordination and case management, as well as the perspective of regulated entities about the effectiveness of the current rules. Recognizing that HHS needs to work within the confines of the overarching statutes when developing any future regulatory modifications, the NAHU membership would like to encourage the Administration to take a comprehensive look at how the current rules are working. Your goals should be decreasing the regulatory burden on covered entities and business associates, facilitating information sharing, actually protecting patients from current privacy threats and making sure they have access to the best quality care.

When reviewing the request for information, it was clear to our members that all of the questions posed by HHS assume that all covered entities and businesses associates are fully educated about their current compliance responsibilities and obligations and that they have efficient practices in place to fully and consistently adhere to those requirements. Furthermore, rules presume that all business-associate contracts are well thought out, entity-specific and executed consistently. Quite frankly, our members’ market-based experience indicates that, in most cases, precisely the opposite is true. While certainly some providers, payers, and healthcare clearinghouses have an excellent handle on their privacy practices, as many do not, and their compliance practices are piecemeal at best. This pattern of inconsistent privacy management and compliance persists with the vast range of individuals and companies that may qualify as downstream risk and business associates.

The rules and required procedures are not only costly and complicated to implement, but they are also overwhelming to many covered entities and business associates. It is our membership’s observation that hundreds of thousands of business owners nationally (such as those who operate self-funded health plans, including Flexible Savings Accounts and Health Reimbursement Arrangements as part of their employee benefit plans) aren’t even aware that these rules apply to their operations. When informed of the requirements and their scope and cost, many entities do not even know where to begin. In our experience, it is not until a covered entity discovers a breach that contract enforcement gets serious and, given the range of downstream risk and realities of enforcing privacy requirements, compliance holes abound.

As such, there are widespread HIPAA privacy disparities across all sectors of the healthcare sphere, and related misinformation and misunderstandings. People and institutions that do not clearly understand the scope of the rules, and the associated rights and responsibilities created by the HIPAA and HITECH privacy and data security requirements, routinely hinder patient care and the appropriate transfer of information. People and entities who fear violations but do not truly understand what is required or permitted and why often get hung up on small requirements and technical details, or invent requirements and information-sharing obstacles. However, these
same entities often miss bigger-picture data-security concerns or are out of compliance with other aspects of the rules. Our members also observe individuals and providers coming up with low-tech workarounds to rules that, while frequently well meaning, can actually subvert privacy and patient care.

The struggles with the existing privacy rules make true healthcare transformation difficult, so in addition to broadly reviewing the current requirements to see if they make sense for today’s patients, payers and providers, our organization encourages HHS to carefully consider how any changes to be made will be communicated and enforced. In our view, a comprehensive educational campaign for covered entities and business associates, coupled with extensive and easy-to-use compliance resources and sensible and consistent safe harbors and enforcement practices, is essential to the success of any measure to protect patient privacy.

**Responses to Specific Questions in the Request for Information**

**Questions 1-4 – Timeframe of the Release of PHI**

These questions all concern the typical timeframe and processes covered entities with regard to the release of protected health information (PHI). It is our membership’s experience that the speed of and methods for PHI distribution can vary substantially by a specific covered entity and by type of covered entity. It is important to note that covered entities can range from enormous health systems to small employers that have direct access to PHI because they operate self-funded health plans. Any requirement to change the timeframe of PHI disclosures, both for paper and electronic transmissions, should be scaled, and the type and size of the covered entity should be taken into consideration.

**Question 7 – Requiring Disclosures to Other Covered Entities**

NAHU believes that for care-coordination purposes and also to facilitate value-based payment arrangements, it may be practical to require certain disclosures of PHI to other covered entities. This idea should be explored in future rulemaking.

**Questions 9-11 – Disclosures to Entities Not Covered by HIPAA**

NAHU believes that caution should be exercised concerning disclosures to any entity that is not covered by the scope of HIPAA privacy rules and that the current requirements, which permit but do not require such disclosures, should continue to be the regulatory standard. While perhaps specific exceptions might be developed if necessary for emergency patient care, in general, our association believes that there are significant risks and consumer-protection and administrative concerns that may arise with required and routine disclosures to non-covered entities.

**Question 20 – Public Information and Education**

Question 20 addresses the need for additional public information and education about the existing privacy rules and ponders if merely extra HHS attention in this area, rather than further rulemaking, would be sufficient to address the issues covered in this request for information. NAHU believes that the need for additional HIPAA privacy rule education and compliance resources cannot be overstated, particularly for smaller entities and business associates, and we hope that HHS will dedicate time and resources to this now. However, we do not think that these efforts alone will solve care-coordination issues and the issues that parents and other caretakers are experiencing concerning privacy and accessing care, treatment and payment information for children and other family members suffering from substance-abuse disorders and severe mental illnesses, and that future rulemaking
is required. Furthermore, when HHS ultimately moves to the implementation phase of any future privacy rulemaking, we request the dedication of substantial resources to public information and education, as well as compliance resources and transitional good-faith compliance protections for all affected entities.

Questions 23-25 – Parents and Other Caregivers
This series of questions specifically address issues that parents and other caregivers may experience with the HIPAA privacy requirements when attempting to care for and help children and other close family members who may be suffering severe mental illnesses and or substance-abuse problems. NAHU members often assist parents and other family members with health insurance claims and payment concerns related to such treatment, and our members have observed parents and caretakers struggling to obtain needed information during trying and emotionally charged circumstances. This is often a time when family members resort to low-tech subterfuge to get access to the required information. While usually done with the best of intentions, NAHU believes that the commonality and necessity of this type of deception is an indicator of a much bigger problem that should cause HHS real concern.

Question 24 asks specifically about parents being denied access to the records and PHI of minor children, and our members report that this does sometimes happen or, more commonly, parental access is delayed, and the processes can be challenging to navigate, particularly if the parent is non-custodial or is not the primary health insurance subscriber. These obstacles are often the result of misinformation on the part of a covered entity or a lack of understanding of the HIPAA rules and related state-level protections by specific employees of covered entities. While the parent may be able to gain the necessary information eventually, that does not mean that the process isn’t sometimes a hindrance to a parent during a time of crisis or when a parent is trying to deal with complicated payment issues.

Question 25 B asks if specific exceptions should be made for parents and caregivers concerning children and spouses who have reached the age of majority but may be suffering from a severe addiction or mental illness. NAHU members often have to assist parents, spouses and caregivers with securing payment arrangements for treatment and related claims issues in these cases, and our members report that the obstacles for family members can be significant, particularly since they often occur in times of great crisis. There can also be costly and time-consuming legal concerns for parents of special-needs children who need help navigating a lifetime of complicated medical decisions and payment issues. While our members do not have any specific suggestions for a fail-safe solution to this complex problem, we feel that it is a critical issue that deserves examination and likely further regulatory action.

Questions 31-42 – Accounting of Disclosures for Treatment, Payment and Healthcare Operations
This series of questions concerns the accounting of disclosures made by covered entities and business associates for treatment, payment and healthcare operations. NAHU has significant concerns about expanding accounting requirements in this area, particularly for business associates. We urge HHS to consider the need for additional disclosure requirements, the cost and administrative burden of such requirements and, what, if any, the benefits would be to consumers and covered entities if changes were made in this area.
NAHU sincerely appreciates the opportunity to provide information on this critical and timely topic. If you have any questions or need additional information, please do not hesitate to contact me at either (202) 595-0787 or jtrautwein@nahu.org.

Sincerely,

Janet Stokes Trautwein
Executive Vice President and CEO
National Association of Health Underwriters