February 8, 2019

The Honorable 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
Attention: RFI, RIN 0945-AA00

Re: Request for Information on Modifying HIPAA Rules to Improve Coordinated Care

Dear Director Severino,

The Association for Behavioral Health and Wellness (ABHW) appreciates the opportunity to respond to your Request for Information (RFI) on Modifying HIPAA Rules to Improve Coordinated Care.

ABHW is the national voice for payers that manage behavioral health insurance benefits. ABHW member companies provide coverage to approximately 200 million people in both the public and private sectors to treat mental health, substance use disorders (SUDs), and other behaviors that impact health and wellness.

We thank you for recognizing the need to improve coordinated care, particularly in regard to addressing the opioid crisis and serious mental illness. However, modifying the Health Insurance Portability and Accountability Act (HIPAA) is not sufficient for improving coordinated care. 42 CFR Part 2 (Part 2) is the true roadblock to integrating care for persons with opioid and other SUDs. ABHW member companies work to coordinate patient care but face challenges because of Part 2. These outdated 1970s federal regulations governing the confidentiality of drug and alcohol treatment and prevention records set
requirements limiting the use and disclosure of patients’ SUD records from federally assisted entities or individuals that hold themselves out as providing, and do provide, alcohol or drug use diagnosis, treatment, or referral for treatment.

Patients must submit written consent prior to the disclosure of their SUD record. Obtaining multiple consents from the patient is challenging and creates barriers to whole-person, integrated approaches to care, which are part of our current health care framework. In situations where the patient does not give written consent, payers are prohibited from sharing this information with the health care providers on the front line caring for patients with SUDs.

Separation of a patient’s addiction record from the rest of that person’s medical record creates obstacles and prevents patients from receiving safe, effective, high quality substance use treatment and coordinated care. ABHW members say Part 2 is one of the biggest – if not the biggest – barriers to fighting the opioid crisis. Aligning Part 2 with HIPAA for treatment, payment, and health care operations (TPO) should be the first step toward improving coordinated care.

ABHW has focused its response to the RFI on section (b), entitled, “Promoting parental and caregiver involvement and addressing the opioid crisis and serious mental illness”. Our responses to the questions in that section follow.

22) What changes can be made to the Privacy Rule to help address the opioid epidemic? What risks are associated with these changes? For example, is there concern that encouraging more sharing of PHI in these circumstances may discourage individuals from seeking needed health care services? Also is there concern that encouraging more sharing of PHI may interfere with individuals’ ability to direct and manage their own care? How should OCR balance the risk and the benefit?

The opioid epidemic has challenged ABHW member companies in their treatment of a whole person when they do not have access to the patient’s SUD record as a result of Part 2. ABHW members do not have specific recommendations on how to modify HIPAA to override restrictions from Part 2. Rather, as mentioned above, aligning Part 2 with HIPAA for TPO is a needed change that would vastly improve payers’ ability to address the
opioid crisis more effectively.

Because health care professionals currently must learn and understand two sets of privacy standards, it would be beneficial if HIPAA could emphasize the differences between what Part 2 covers and what HIPAA covers.

For example, HIPAA’s “Friends and Family” exception allows the covered entity to talk to persons known to be involved in a patient’s care, as long as the patient is given the opportunity to object. For health plan staff, that involves either the patient deciding to hand the phone to a family member, or the family member being asked if the patient can come to the phone and provide verbal approval for the health plan to talk with the family member. However, if the subject of the conversation is the patient’s SUD care, the health plan cannot rely on the HIPAA exception; Part 2 has no similar provision and no provision in any way that allows for verbal consent.

Stringent and differing state laws present another barrier to understanding when protected health information (PHI) can be shared. A report that shows how these different standards impact care coordination would help to provide additional clarification for payers. This study could address implications for states that have varying guidelines, show the barriers that exist to treating the whole person, and highlight the barriers that exist with old statutes.

23) How can OCR amend the HIPAA Rules to address serious mental illness? For example, are there changes that would facilitate treatment and care coordination for individuals with SMI, or ensure that family members and other caregivers can be involved in an individual’s care? What are the perceived barriers to facilitating this treatment and care coordination? Would encouraging more sharing in the context of SMI create concerns similar to any concerns raised in relation to the previous question on the opioid epidemic? If so, how could such concerns be mitigated?

Despite a significant amount of education, there seems to be a lack of awareness and understanding of HIPAA. ABHW members and other health care professionals continue to face challenges around what is, and can be, permissible to share under HIPAA. As such, ABHW recommends additional
technical guidance and fact sheets for training purposes. Practical examples of every day use and disclosure would help health care professionals better understand the privacy rule and apply it accurately.

Furthermore, the wide range of stringent state HIPAA laws continue to complicate the understanding and application of the privacy law. State laws that are more restrictive than HIPAA impact the ability to share PHI in the SMI population. For example, some state laws restrict the sharing of mental health records in a similar fashion to the way Part 2 prohibits the sharing of addiction records.

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.

In this instance, the challenge is state law, not HIPAA. For example, many states allow 15- or 16-year-old children to provide authorization for their own treatment without parental approval, and ABHW member companies are unable to report information to the parents without written consent from the children. Consistency across all state HIPAA laws is critical. If HIPAA could create rules that preempted states, or institute a national standard, that uniformity could be achieved.

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?

Much of HIPAA is written for doctors and hospitals without seeming to apply directly to the payer space. Patients often call payers about availability of benefits, not necessarily clinical records. ABHW members sometimes face a barrier when the subscriber to the account requests information about remaining benefits on the family’s account. It can be tricky for a payer to
provide benefit information without sharing PHI. Though the payer might only share benefit information to that customer, details about a particular family member’s PHI could potentially be deduced by the customer. For example, one ABHW member company had an account holder call the health plan to determine how close they were to meeting their deductible. Once given that information, the account holder was able to deduce that their child received care, of which the parent was not aware, because the parent had not spent that amount on health care services.

Additionally, HIPAA and Part 2 have differing rules regarding the ability to speak to parents about their minor children’s care. They both start by looking at what the minor is permitted to consent under state law. The major difference is that HIPAA’s provision for the minor controlling his or her own PHI does not apply unless the minor actually received that service pursuant to their own consent, without parental involvement. Part 2, on the other hand, does not go further than what the state law would allow the minor to do on his or her own. So, when health plan staff is talking with parents (who they find are almost always involved in their child’s care), they can talk freely to the parent about their child’s mental health services, but are prohibited from talking about any SUD services, unless the minor has provided written consent. Health plans rarely have that written consent. This leads to friction between health plan staff and parents, especially when the child has co-occurring mental illness and SUD.

Clarification would be helpful in order to better assist the customer with accurate information while protecting other family members’ privacy. Generally, ABHW members would like to see more guidance around how to apply HIPAA in payer settings. To better deal with the fine line between providing benefit information and PHI, ABHW recommends the creation of a Consumer’s Guide to Requesting Information from a Payer. This would include guidance for both the payer and the customer about what to expect when requesting or giving information.

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?

State laws adequately safeguard an individual’s information. However, once again, a lack of clarity exists here. ABHW recommends additional guidance, such as a report – like that described in our answer to question #22 – to show what already exists in state laws.

In addition to improving coordinated care within the confines of HIPAA, ABHW urges you to initiate a separate rulemaking process for Part 2. Antiquated Part 2 regulations are not compatible with the way health care is delivered currently. In order to modernize these regulations, Part 2 needs to harmonize with HIPAA to allow for the transmission of SUD records without written consent, for treatment, payment, and health care operations. This will promote integrated care and enhance patient safety, while providing health care professionals with one federal privacy standard for all of medicine.

Thank you for considering our recommendations. If you have any questions, please contact me at (202) 449-7660 or greenberg@abhw.org.

Sincerely,

Pamela Greenberg, MPP
President and CEO
Association for Behavioral Health and Wellness