February 12, 2019

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

RE: Department of Health and Human Services, Office for Civil Rights RIN 0945-AA00

Dear Secretary Azar and Director Severino,

The American Academy of Nursing (Academy) submits the following comments in response to the Request for Information (RFI) on Modifying HIPAA Rules to Improve Coordinated Care.

The Academy applauds the Office for Civil Rights' (OCR) solicitation for public comments on provisions of the HIPAA’s Rules that present barriers that limit or discourage coordinated care among individuals and covered entities and that impede the transformation to value-based health care without meaningfully adding to patients’ privacy and security concerns regarding their protected health information (PHI) and their ability to control the use, disclosure, and accessibility of their PHI.

The Academy serves the public by advancing health policy through nursing expertise to improve healthcare delivery and outcomes. Ensuring all consumers have access to safe and affordable high-quality care is a priority of the Academy and its 2700 fellows. These Academy comments are premised upon the belief that patients’ needs and interests must remain the focus of health policy. While well-coordinated care assists health providers, hospitals, and insurers in fulfilling each of their professional roles, the goal of care coordination and value-based care is to improve patient outcomes. Similarly, rules that are either written intentionally or in such a way as to permit interpretation that places providers, hospitals, and/or insurance companies’ concerns over patients’ rights and their ability to readily use, disclose, and make accessible their PHI must be changed. Patients’ rights and needs must remain the focus and the central underpinning to policy decisions.

Nurses have long played an integral role in improving patient care through the development of effective and innovative care coordination models.¹ Care coordination provided by nurses and other qualified health professionals is essential to delivering high quality care and achieving patients’ best outcomes. Therefore, the Academy proceeds on the understanding that Health Information Exchange (HIE) and patient-provider communication, as regulated by the HIPAA rules, are together foundational to care coordination. HIE enables the sharing of patient information, across organizational boundaries and despite differing information systems, in support of individual patient care. Systems of HIE and communication must adequately address privacy and security concerns. However, it is essential that health providers approach privacy and security in a way that enables highly effective systems of care

coordination without limiting patients’ rights and ability to use, disclose, and make accessible their health information as they see fit.

The Academy supports funding prioritization for research and methods that address social and behavioral determinants of health into the electronic health records (EHR) as well as research that addresses barriers to exchange such data across care settings to support care coordination. The ultimate goal is to support patients in their own e-community and provide resources for successful patient and family engagement. To this end, the Academy supports adopting the social and behavioral determinants of health (SBDH) as a common assessment standard and the use of information by the healthcare team as the foundation to collaborate in developing a plan of care that is individualized for each patient across the continuum of care.²

In response to the RFI, the Academy highlights the following HIPAA concerns that may prohibit success toward care coordination and care outcomes:

**Improve Methods to Identify and Match Individuals Across Care Settings:**
The Academy recommends improving methods to identify individuals across care settings. A key factor to successful care coordination within and across regions of the U.S. is to accurately match individuals and their health data. This is particularly important when SBDHs are added to already sensitive health information. While methods to identify patients and algorithms for patient identity matching have improved, patient identity matching continues to pose a substantial challenge. Implementation of a universal patient identifier, or alternatively, advanced methods of patient identity matching, is essential to the long-term success of HIE in supporting care coordination.³

**Establish a harmonized, nationwide approach to the protection of PHI:**
The Academy recommends establishing a harmonized, nationwide approach to the protection of sensitive PHI. A persistent barrier to HIE for the prescribed purpose of developing effective care coordination is the difficulty and confusion in navigating varying state and federal privacy laws. Protections relating to the exchange of sensitive health information vary considerably from state to state, and may pertain to conditions ranging from genetic disorders and sexually transmitted diseases to HIV/AIDS and substance abuse treatment. Additionally, federal law and regulations, such as 42 CFR Part 2, further regulate privacy and security related to mental health care services. As a result, health care providers and health care organizations are often reluctant to participate in HIE, fearing that information with special protections will be unintentionally disclosed.⁴ Technologies such as date segmentation approaches capable of navigating this situation are not sufficiently mature. This poses a key barrier to exchanging health information in support of care coordination, within and across state lines. Moreover, it creates important safety concerns. Variable exclusion of important information about diagnoses or medications from HIE activities could lead to unsafe, potentially lethal prescribing or treatment, and creates potential discontinuity across all care with an emphasis on mental health care. These inconsistent state and federal privacy laws also displace the focus away from how best to serve patients’ needs and interests to instead about protecting covered entities from potential liability.

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Establish a harmonized, nationwide approach to patient consent for HIE with the preferred model being “opt out:”
The existence of varied patient consent requirements among states is a persistent barrier to the advancement of HIE as a basis for care coordination. While many states have adopted successful models, others lag markedly behind. States that require patients to “opt in” to HIE have untenably poor participation, and the differences among states in their consent requirements impede HIE beyond state lines. Harmonizing the approach to patient consent for HIE, preferably with a nationwide “opt out” model, will improve care coordination and still protect the privacy and security of patients’ PHI.

Provide guidance for privacy and security in electronic patient-provider communications beyond patient-portals (eHealth):
Healthy People 2020 indicates consumer engagement in health technology is critical to the population of the U.S. prioritizing a goal to “use health communication strategies and health information technology (IT) to improve population health outcomes and health care quality, and to achieve health equity.” The United States strategies for engagement have focused primarily on use of patient portals and EHRs to engage communities and healthcare consumers. While patient portals are showing promise and creating value for healthcare consumers in access to their health information, there are also complementary modalities of health IT communications that can be used to reinforce and strengthen informing and engaging communities and targeted populations to improve health. In Canada, the use of social media (e.g., Facebook, Twitter, LinkedIn, etc.) is increasingly used in healthcare, and by government agencies to engage citizens. Governments and healthcare sectors have identified social media as an important priority in emerging national health policies.

The HIPAA privacy rule explicitly addresses email but does not address PHI in the context of electronic patient-provider communication via SMS/text messaging or social media platforms. In order to effectively communicate and engage with patients and their families for care coordination, nurses and other health care providers need to use forms of communication that patients will utilize. In the absence of clear guidance, many health care providers may avoid crucial opportunities to communicate with patients and their families using any modality other than a voice call or patient portal. However, these forms of communication are increasingly misaligned with the way patients and their families would like to communicate.

Provide guidance on requiring covered entities to share PHI for treatment purposes:
Today’s health care system often involves patients moving from one facility or type of facility to another during the course of their treatment. The health and well-being of these patients is dependent not only upon their safe physical transport, but also the timely transport of their PHI. Patients arriving at a new covered-entity without the providers assuming their care at the new facility having access to their PHI not only breaks down care coordination, but jeopardizes patients’ health. Requiring covered entities to share PHI with other covered entities for treatment is essential to achieving high-quality care and patients’ best outcomes.

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Conclusion:
The delivery and receipt of high quality value-based care in the United States requires timely, safe, and secure exchange of PHI between covered entities in order to facilitate effective care coordination, as well as patients’ ability to readily use, disclose, and make accessible their PHI to those providing their care. The Academy thanks the Office for Civil Rights for extending this RFI to stakeholders so that modifications may be made to the HIPAA Rules to break down existing barriers to effective care coordination and to promote high quality value-based health care that focuses on patients. Should you have any questions concerning the Academy’s recommendations, please contact Kim Czubarkuk, the Academy’s policy manager, at kczubarkuk@aannet.org.

Sincerely,

Karen S. Cox, PhD, RN, FACHE, FAAN
President
American Academy of Nursing