NASDOH
NATIONAL ALLIANCE TO IMPACT THE SOCIAL DETERMINANTS OF HEALTH

May 5, 2021

Robinsue Frohboese, Ph.D., JD
U.S. Department of Health and Human Services
Office of Civil Rights
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW, Washington, DC 20201

Attention: Notice of Public Rulemaking (NPRM) on Modifying HIPAA Rules to Improve Coordinated Care, RIN 0945-AA00

Dear Dr. Frohboese,

On behalf of the National Alliance to impact the Social Determinants of Health (NASDOH), we appreciate the opportunity to provide our collective comments on how the Health Insurance Portability and Accountability Act (HIPAA) Rules could better promote coordinated and value-based health care, particularly as it relates to the ability of covered entities to disclose protected health information (PHI) to social service and other third-party agencies that provide health-related services.

NASDOH is a group of stakeholders working to systematically and pragmatically build a common understanding of the importance of addressing social needs as part of an overall approach to health improvement. We seek to make a material improvement in the health of individuals and communities and, through multi-sector partnerships within the national system of health, advance holistic, value-based, person-centered health care that can successfully impact the social determinants of health. NASDOH brings together health care, public health and social services expertise, local community experience, community-convening competence, business and financial insight, technology innovation, data and analytics competencies, and policy and advocacy acumen to assess and address current regulatory frameworks, funding environments and opportunities, and practical challenges to implementing and sustaining social determinants of health efforts.

Sharing information across organizations and sectors is integral to addressing social needs in communities throughout the nation. Below, NASDOH offers recommendations on questions posed in the proposed rule related to adding a new subsection 164.506(c)(6) which would expressly permit covered entities to disclose PHI without obtaining a valid authorization from the individual to social service agencies, community-based organizations, HCBS providers, and other similar third parties that provide health-related services to specific individuals for individual-level care coordination and case management. *NASDOH's comments apply specifically to sharing with social services agencies, community-based organizations, and HCBS providers to meet social needs and address SDOH.*

a. ***Whether the proposal to create an express permission to disclose PHI to certain third parties for individual level treatment and health care operations would help improve care coordination and case management for individuals, and any potential unintended adverse consequences.***

NASDOH supports OCR creating an express permission to disclose PHI to certain third parties for individual-level treatment and health care operations.

NASDOH is not supporting fundamental changes to the HIPAA Privacy rules but as stated in the NPRM, there continues to be confusion about when disclosures without obtaining a valid authorization from the individual are permitted and the scope of permission to disclose despite guidance on the topic. In some cases these referrals may be covered as part of care coordination

and case management but in cases where it is not or where there is lack of clarity, creating an express permission to disclose PHI for individual-level care coordination and case management activities, OCR can help improve care by addressing allowable uses and disclosure of PHI under the existing Privacy Rules. This will encourage appropriate application of the law and allow individuals to benefit from information sharing and help ensure they receive needed services at the right time.

An important aspect of improving health is appropriate information sharing between health plans and providers, and third parties who provided needed services and supports. When information communication and coordination is fragmented, there are unfavorable consequences, which include inefficient use of resources, lower quality or care, and worse health outcomes. It can also be a source of frustration and confusion and add unnecessary burden on individuals needing services and supports. For example, if a health care provider were to refer a patient with diabetes to a food bank, it would be to the benefit of the individual that the food bank be made aware so dietary accommodations should be made and, if needed, nutrition support can be provided. In such a case, being able to share this important health information would ensure that individuals get the services that are most appropriate to them. Further, better information sharing between health care and third-party entities providing services would reduce the burden on individuals to reshare their health information at every point they interact with the health and social system. NASDOH members observe that, in many cases, individuals expect this information to be shared and is appreciated because it reduces burden on individuals to steward their data–particularly when they do not have the capacity to bear the responsibility–and repeat their medical history during each and every interaction.

Despite the potential benefit, we observe barriers to sharing information on both ends: health care providers often do not share important information, and community-based organizations do not accept information, out of fear they will violate HIPAA. NASDOH supports the rule being modified to expressly grant permission because it can assuage concerns which inhibit essential and allowable information sharing to the benefit of individuals and create efficiencies in the system.

b. Whether the proposal poses any particular risks for individuals related to permitting disclosures without authorization for individual-level care coordination and case management activities that are health care operations (i.e., those that are conducted by health plans) in addition to individual-level care coordination and case management activities that constitute treatment (i.e., those that are conducted by health care providers).

NASDOH does not believe that the proposal introduces any greater risk than exist already under the current law. We support OCR creating express permission because we believe it will improve case management and care coordination, and positively impact health. However, NASDOH believes that OCR should emphasize that only *minimum and necessary information* be shared. We believe this standard can help minimize the existing risk. For example, if a patient regularly receives delivery from a food bank, the food bank should be notified if the patient is currently admitted to a hospital so that food service can be temporarily paused. However, it is not relevant, nor to the benefit of the patient, for any additional PHI to be shared with the food bank in this case. If additional and unnecessary information that does not pertain to the provision of care or services is shared, it could be a harm to the patient. For example, if a patient experiencing housing insecurity were to be referred to a housing support system and unnecessary information was shared, like a positive drug screening test result, it could jeopardize the services offered to the patient and ultimately impact their health.

Additionally, individuals have the right to know why their health and related information is being collected and shared, when and why referrals are made, and what the benefits may be to them. Care coordination and case management should be done with the individual, not to the individual. Whether or not there is the express permission, providers should always engage patients in their care planning and discuss all referrals with individuals before they are made. If during those discussions, or at any other time, a patient expresses preferences about their data, they should be respected. NASDOH recommends that OCR provide guidance to covered entities about consumers' rights and how best to comply with consumers' invocation of the individual right of access and direction of

health information to third parties. This guidance is necessary to avoid any unintended consequences related to breach of consumer privacy when a patient expresses a preference, even if sharing is allowable.

c. *Would the proposed change remove perceived barriers to disclosure of PHI, as appropriate, to social services agencies, community-based organizations, and HCBS providers to better enable care coordination and case management? Are there other entities the Department should identify in regulatory text as examples of appropriate recipients of PHI under the proposed permission?*

NASDOH believes that the proposed change would remove many perceived barriers to disclosure of PHI to social service agencies, community-based organizations, and HCBS providers for care coordination and case management. We support OCR's proposal to include examples of the third-party recipient entities which are appropriate recipients of PHI in regulatory text to further ease confusion and concern.

It is our understanding that, in addition to health plan and health care provider hesitancy, many social care organizations, including housing support agencies and food banks, are extremely reticent to accept data, even when it could improve the services they provide, because of apprehension related to complying with HIPAA requirements. For entities not already familiar with and subject to HIPAA (e.g., community-based organizations), they often misunderstand or fear even when they do not need to. By clearly expressing when and to whom data can be shared, OCR would also assuage concerns from these community-based providers who are essential in partnering with health care organizations to improve health.

Additionally, educational resources tailored to entities that are generally not subject to HIPAA would be helpful to combat misinformation and misperception and facilitate information sharing.

d. *Should the proposed change be limited to care coordination and case management for a particular individual as proposed, or should it also include population-based efforts?*

We support OCR's proposal to limit the scope of the permission to disclosures by covered entities for care coordination and case management for individuals rather than population-based activities. As OCR noted, limiting allowable disclosures to only those for care coordination and case management at an individual level would make this express permission akin to disclosures for treatment. Again, we must reiterate our earlier recommendation that OCR specifically state that only minimum and necessary PHI be shared. To preserve privacy and security, it is essential that only information which is relevant and to the benefit of a patient's health be shared.

e. *Should the Department specify the types of organizational entities to be included as recipients of PHI in this express permission in regulation text, as well as limitations or exclusions, if any, that should be placed on the types of entities included? If yes, what types of organizational entities should be included or excluded?*

Yes, an illustrative list of organizational entities to be included in this express permission is helpful. The list need not be comprehensive. Additionally, NASDOH believes security and privacy should be paramount to data sharing. NASDOH recommends that OCR should specify in the express permission regulation text that, in addition to the types of organizations to be included, that disclosure of PHI should be limited to organizational entities that have the appropriate infrastructure in place to successfully secure and protect PHI. Only organizational entities that can meet this requirement should be included as recipients in the express permission.

Although we believe that this information should be shared to promote better care coordination and case management, we also feel strongly that patient data should be safeguarded, and privacy be maintained to the fullest extent possible. NASDOH members observe that many organizations have the capacity to protect information privacy.

f. Should the Department limit the proposed permission to disclose PHI to circumstances in which a particular service provided by a social services agency, community-based organization, or HCBS provider is specifically identified in an individual's care plan and/or for which a social need has been identified via a screening assessment? Should the Department require, as a condition of the disclosure, that the parties put in place an agreement that describes and/or limits the uses and further disclosures allowed by the third-party recipients?

NASDOH believes that it would be a good indication to a health care provider that it would be appropriate to disclose the minimum and necessary information about an individual patient to a social services agency, CBO, or a HCBS provider when a particular service need was identified through a screening assessment or in an individual's care plan. In this case, there would be a clear and compelling reason to share information. However, we do not believe that these should be the only circumstances in which information is shared. For example, some health care entities use specific care planning documents that may not always be updated and properly documented. Similarly, a patient may disclosure to their health care provider that they are in need of or using a particular social service, but that need was not identified by a screening assessment performed by the health care provider. These are circumstances in which it may also be appropriate to share. Therefore, our recommendation is that a rigid requirement to meet the criteria of documentation in a care plan or screening assessment not be put in place.

We support the Department putting requirements in place that limit the use and further disclosures by third-party recipients of information. This is important for protecting individual's privacy, since as discussed previously, these third-party recipients are generally not subject to HIPAA. Nonetheless, they should still be required to protect individual's information and be prohibited from disclosing it further.

***

We appreciate the opportunity to provide NASODH's views and recommendations on how OCR can modify the HIPAA Rules to clarify and better promote coordinated and value-based health care. We are happy to discuss any of the information outlined above or provide further assistance that would be valuable. For more information on NASDOH, please visit our website at www.nasdoh.org or contact Lauren Ward at Lauren.Ward@leavittpartners.com

Sincerely,

Sara Singleton

Sara Singleton
Principal, Leavitt Partners and Advisor to NASDOH