

Robinsue Frohboese Acting Director, Office for Civil Rights U.S. Department of Health & Human Services 200 Independence Avenue, SW Washington, DC 20201

RE: Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement (RIN 0945-AA00)

Dear Ms. Frohboese,

Thank you for the opportunity to respond to the Proposed Modifications to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement (NPRM). Unite Us, and the Unite Us partners listed below, welcome the efforts of the Office for Civil Rights (OCR) to achieve value-based care by removing barriers to coordinated care. We have outlined below the specific provisions of the NPRM we believe will support this important goal.

### Background on Unite Us

Founded in 2013, Unite Us builds coordinated care networks of health and human service providers to address all determinants of health. Originally created to serve veterans and military families, Unite Us has grown into a national movement to connect everyone with the care they need. Unite Us' intuitive platform enables health and social service organizations to coordinate and manage services for their clients (referred to in this comment letter as "individuals" for consistency with HIPAA), track referrals and outcomes together, and securely share information to facilitate care coordination. Our goal is to ensure every individual, no matter who they are or where they live, can access the critical services they need to live happy and healthy lives.

More than just a technology company, Unite Us' national growth is due to our proven community engagement process. Our comprehensive network-building and change management process creates value for community partners with a focus on increasing access to services and empowering the community to drive greater impact.

Over the past eight years, Unite Us has built coordinated care networks in 42 states, which include over 200,000 professional health and social care staff, to securely coordinate services for shared individuals with multiple co-occurring needs. In just the last two-and-a-half years, the networks powered by the Unite Us Platform have enabled almost 400,000 unique and documented service episodes by social care organizations, delivering services such as housing, mental and behavioral health, transportation, education, employment, legal, food, and benefits assistance. The rate at which these organizations are working together on the Unite Us Platform is growing exponentially, illustrating the growing need for this integrated work among health and social care organizations.

Trust and transparency are the cornerstones of the Unite Us Platform. Unite Us has implemented a robust, individual-centered, and health equity-driven process that requires each individual seeking services to consent to share their information before any referrals can be sent on their behalf via the Unite Us Platform. We designed this process to protect individual privacy, while simultaneously removing barriers individuals face when seeking services and alleviating the challenges faced by health and social service providers when coordinating care.

#### **General Comments**

Unite Us shares OCR's goal of achieving value-based health care by supporting the information sharing necessary to ensure a whole-person approach to care. We commend OCR's efforts to update the Privacy Rule to remove barriers to coordinated care and facilitate information sharing to connect people to the services they need outside of traditional health care settings. As the national leader in deploying community-wide coordinated care networks of health and social services, we believe our perspective and experience will benefit OCR as it considers these changes.

Unite Us believes that achieving value-based care and addressing social determinants of health requires a whole-person approach to care coordination. This means empowering community health workers and social care providers to participate in improving individual health and well-being through coordination of social service activities. Research shows that up to 80% of health outcomes are driven by social needs and social determinants, making social care a critical component of health care treatment and operations. To address these needs, covered entities providing health care must be empowered to share protected health information (PHI) with CBOs.

Unite Us supports the proposed modifications to the Privacy Rule and believes the modifications will go a long way toward advancing a whole-person approach to care. In support of OCR's goal to address social determinants of health by advancing information sharing, Unite Us recommends that OCR consider the following:

- clarify the definition of health care operations to encompass all care coordination and case management activities, including social care coordination, but go farther to explicitly include social care coordination in the definitions of health care operations and treatment;
- broaden the proposed exception to the minimum necessary standard to include disclosures of PHI
  to CBOs and organizations that enable or facilitate case management and care coordination
  activities between covered entities and CBOs;
- avoid adopting regulations that would prohibit covered entities from sharing information with social service providers that are not explicitly described in care plans or that have not signed a Business Associate Agreement (BAA) with a covered health care provider or health plan; and
- clarify that permissible disclosures of data subject to 42 C.F.R. part 2 (Part 2) align with HIPAA or that the Department of Health and Human Services swiftly adopt such modifications in the forthcoming Part 2 regulations implementing the Coronavirus Aid, Relief, and Economic Security Act.



### **Specific Comments**

1. Amending the Definition of Health Care Operations to Clarify the Scope of Care Coordination and Case Management (III.C)

Unite Us strongly supports OCR's effort to clarify the definition of health care operations to encompass all care coordination and case management activities, including social care coordination. As noted by OCR, Unite Us has similarly observed that, despite published guidance to the contrary, some covered entities interpret the existing definition of health care operations to include only population-based care coordination and case management. This interpretation has the unfortunate effect of excluding individual-focused care coordination and case management.

Social care is a critical component of health care treatment and operations. Yet covered entities are only beginning to coordinate with social care organizations to address social needs. This coordination failure is exacerbated by a lack of clarity on the types of information that can be shared with social service entities without triggering additional HIPAA requirements, which services can be included in case management and care coordination activities, and a historical lack of technology infrastructure to securely share such information.

OCR's proposed rule makes clear social care is an integral part of individual care. By clarifying the definition of case management and care coordination activities, OCR will enable improved health outcomes by removing barriers to information sharing. Consider an example the Unite Us team regularly encounters: a clinical care coordinator would like to secure permanent supportive housing for an individual with a disability. To secure such housing, the coordinator believes it is necessary to share documentation with a community-based housing organization regarding the disability and the housing accommodations that would best support the individual. Given the current confusion, the coordinator may not feel comfortable directly sharing this information with the community-based housing organization out of concern for violating the Privacy Rule. As a result, the coordinator shifts the burden of gathering the required documentation and arranging housing to the individual seeking care.

To eliminate any confusion regarding the scope of the regulations, Unite Us recommends that OCR (1) amend the definition of health care operations to explicitly include coordination of social care needs; and (2) amend the definition of treatment to explicitly include the coordination or management of social services by a health care provider with a CBO. Given social needs often accompany health needs, addressing social needs is critical to improving health outcomes and achieving value-based care, and is therefore integral to case management and care coordination activities.

2. Creating an Exception to the Minimum Necessary Standard for Disclosures for Individual-Level Care Coordination and Case Management (III.D)

Unite Us supports OCR's effort to promote permissible disclosures of PHI for care coordination and case management by adding an express exception to the minimum necessary standard for disclosures to, or requests by, a health plan or covered health care provider for care coordination and case management. Without clear guidelines, health plans and covered health care providers have historically erred on the side



of caution by limiting the information shared with CBOs, thereby hindering the ability of social care providers to identify and serve individuals in need.

It is not uncommon for covered entities to omit key information relevant to an individual's care when communicating with CBOs out of concern for the Privacy Rule's minimum necessary requirements. Our experience working with CBOs has taught us that these omissions can severely impede a CBO's ability to assist the individual. For example, consider a referral from a hospital's care coordinator to a community transportation service to help a patient travel to and from medical appointments. Out of fear of revealing too much, the care coordinator may omit vital information such as the individual's limited mobility, or fail to include sufficient information for the CBO to confirm eligibility for its services.

To facilitate care coordination across sectors, we recommend that OCR broaden the proposed exception to the minimum necessary standard to include disclosures of PHI to CBOs and organizations that enable or facilitate case management and care coordination activities between covered entities and CBOs. This would reduce barriers for health plans and covered health care providers to share vital information with CBOs and support organizations such as Unite Us that facilitate care coordination among health and social service providers.

3. Clarifying the Scope of Covered Entities' Abilities to Disclose PHI to Certain Third Parties for Individual-Level Care Coordination and Case Management that Constitutes Treatment or Health Care Operations (III.E)

Unite Us strongly supports OCR's recommendation to expressly permit covered entities to disclose PHI to CBOs and other third parties that provide health-related services for individual-level care coordination and case management, either as a treatment activity of a covered health care provider or as a health care operations activity of a covered health care provider or health plan.

As previously discussed, despite clear published guidance, there remains significant confusion about whether a covered entity may share PHI with a third party for the purpose of individual-level care coordination and case management. This confusion includes whether such disclosures require prior authorization from the individual, and whether a BAA must be signed with a CBO prior to sharing information.

Lack of clarity on the type of information that can be shared outside of clinical settings and concern about violating HIPAA has historically hindered case managers' and care coordinators' ability to help individuals receive the care they need. For example, a case manager wishing to provide appropriate meals to a patient with diabetes requires communication to the local food pantry that the individual has both a need for food assistance and diabetes-related food restrictions. A lack of clarity about whether this medical information can be shared with the local food pantry could result in the individual receiving meals that would undermine, instead of improve, their health.

Since social needs can be broad and multifaceted, we recommend against adopting unduly restrictive regulations that would limit covered entities to sharing information with social service providers described in the care plan or that have signed a BAA. We often see individuals with a broad set of social needs that cannot be addressed by a single social service entity. Organizations within a coordinated care network often make additional referrals to connect individuals to wrap-around services. Requiring social service



providers to be explicitly listed in care plans would unnecessarily burden both covered entities and CBOs and undermine efforts to coordinate care. In addition, requiring each CBO to meet the strict requirements of a business associate and execute a BAA prior to accessing individual information when coordinating care would place unnecessary regulatory and financial burdens on CBOs, thereby undermining their core mission to provide critical care to those in need.

Unite Us has developed a secure platform to share individual information among health and social service providers. We have implemented a transparent and individual-centered process that explains how personal information will be used to connect the individual with the services they need. No referral can be shared via the Unite Us Platform without the individual's consent. While we encourage broadening permissions to enable the sharing of PHI to improve individual outcomes, we believe educating individuals about how their information will be used is necessary to balance confidentiality with the information sharing needed to enable care coordination.

4. Encouraging Disclosures of PHI when Needed to Help Individuals Experiencing Substance Use Disorder (Including Opioid Use Disorder), Serious Mental Illness, and in Emergency Circumstances (III.F)

Unite Us supports OCR's proposal to allow PHI disclosures when it is in the best interests of the individual experiencing a substance use disorder, serious mental illness, or in an emergency circumstance. As noted in the NPRM, Unite Us has similarly observed that covered entities are reluctant to disclose PHI to third parties about individuals experiencing these health issues, even when the Privacy Rule permits such disclosures.

Unite Us believes integrating mental and behavioral health and substance use services into the care continuum is critical to delivering whole-person care. Individuals who need mental and behavioral health or substance use services are often in need of other kinds of support. We find that approximately 25% of these individuals are referred for housing services and 16% are referred for food assistance, though we expect this significantly underestimates the actual need given the current confusion about permissible disclosures by Part 2 covered organizations to CBOs.

Unite Us believes OCR's proposal will help facilitate care coordination by expanding permissible disclosure of PHI to caregivers and family members of individuals experiencing substance abuse disorders or serious mental illness during emergencies and health crises. However, given the applicability of Part 2 to substance use disorder-related information, we believe Part 2's more stringent requirements will continue to be a barrier to disclosing such information to caregivers and family members. We recommend that OCR clarify the permissibility of such disclosures in the final regulations or in the forthcoming Part 2 regulations implementing the Coronavirus Aid, Relief, and Economic Security Act.

### Conclusion

Thank you for the opportunity to comment on this NPRM and share our perspective and experience on the importance of promoting care coordination among networks of health and social care entities. Unite Us shares OCR's goal of achieving value-based health care by supporting the information sharing necessary to ensure a whole-patient approach to care. We commend OCR for its efforts to remove barriers to coordinate care and facilitate the information sharing necessary to connect people to the services they



need outside of traditional health care settings. We look forward to working with you to address this important issue. If you have any questions or if there is any additional information Unite Us can provide, feel free to contact me or Carlos Uriarte, VP, Regulatory Counsel at carlos.uriarte@uniteus.com.

Sincerely,

## Esther Farkas

Esther Farkas Chief Legal Officer Unite Us

# **Unite Us Partners Joining These Comments**

Andy Burstein Chief Executive Officer Accessible Pharmacy Services for the Blind

Shoshanah Brown, MS, MBA Founder and CEO AlRnyc

Jacob Reider, MD CEO Alliance for Better Health

Brandon Wilson Managing Director for the Veterans Services of the Carolinas Asheville Buncombe Community Christian Ministry

Lashelle Stewart Executive Director Baltimore Healthy Start, Inc.

Shannon Cosgrove Director, Community Health Blue Shield of California

ChristianaCare

Jaime Bland, DNP, RN President and CEO CyncHealth



Ann Mazur Chief Executive Officer EveryMind

Eddie Oliver Executive Director Federation of Virginia Food Banks

Henry Crews Executive Director Green Rural Redevelopment Organization

Dr. Harvey Hinton III Executive Director Healing with CAARE

Hannah Randall Chief Executive Officer MANNA FoodBank

Theresa Reno-Weber President and CEO Metro United Way

Brian Wetter
VP, IT - Infrastructure and Analytics
PacificSource

Lisa David President and CEO Public Health Solutions

Kevin Ewanchyna, MD VP/Chief Medical Officer Samaritan Health Plans

Regina Greer Chief Impact Officer United Way of Greater St. Louis

Nadine Bullock-Pottinga President and CEO United Way of Northern Shenandoah Valley



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M. Norman Oliver, MD, MA State Health Commissioner Virginia Department of Health

Beth O'Connor, M. Ed. Executive Director Virginia Rural Health Association

