

April 13, 2021

Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to,
Coordinated Care and Individual Engagement NPRM RIN 0945-AA00
Hubert H. Humphrey Building, Room 509F
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**

Dear Ms. Richter,

On behalf of the Coalition to Transform Advanced Care (C-TAC), we appreciate the opportunity to provide comments on this proposed rule in regard to its effects on those living with serious illness.

C-TAC is a national non-partisan, not-for-profit coalition dedicated to ensuring that all those living with serious illness, especially the sickest and most vulnerable, receive comprehensive, high- quality, person- and family-centered care that is consistent with their goals and values and honors their dignity. C-TAC is made up of over 150 national and regional organizations including patient and consumer advocacy groups, practitioners, health plans, faith-based and community organizations, and others who share a common vision of improving serious illness care in the U.S.

We have several overall comments on the key aspects of this proposed rule as they will impact the care of those living with advanced illness:

Changes to enhance an individual's right of access to their protected health information (PHI).

We strongly support steps that allow individuals to better access their health information. The more informed a person is about their health and health care, the more informed their medical decisions can be. Making access to peoples' PHI faster and easier supports person-centered care, something that C-TAC has always advocated for.

Our only question on these access changes is the administrative impact they will have on health care organizations. We need to balance these needed changes with allowing organizations adequate time to reconfigure their administrative processes accordingly.

Changes to facilitate value-based health care by modifying provisions that currently limit care coordination and case management communications.

We also strongly support these changes. Patients with serious illness receive fragmented care that is often unaligned with their

preferences later in lifeⁱ. Therefore, anything that promotes better and smoother care coordination is of benefit to this population. We particularly support the proposed rule allowing social service agencies to more easily access patient PHI. C-TAC has long advocated for integrated community models that address peoples' social, emotional, and spiritual needs in addition to their medical ones. Our focus on improving health equity for disadvantaged communities also includes integrating social service agencies as part of someone's overall care.

Our only concern here, however, is that while this rule allows more community organizations to access PHI, it does not address the need for financial or capital investment for information management systems to facilitate doing so.

Changes to encourage disclosures of protected health information (PHI) when needed to help individuals experiencing substance use disorder (SUD) and serious mental illness, as well as in emergency circumstances. Finally, we support these changes as well. We agree that while PHI confidentiality is very important, in some cases privacy needs to be balanced with the need for safety and avoiding harm. C-TAC recognizes and supports family caregivers as key participants in the care of those with serious illness and knows they often struggle with burden from that role. Allowing families of people with serious mental illness or SUD to access their loved one's PHI when appropriate can help provide better and more timely care.

Thank you for the opportunity to comment on this proposed rule. If you have any questions, please contact Marian Grant, Senior Regulatory Advisor, C-TAC, at 443-742-8872 or mgrant@thectac.org.

Sincerely,

Marian Grant

Marian Grant, DNP, CRNP, ACHPN, FPCN
Senior Regulatory Advisor
Coalition to Transform Advanced Care (C-TAC)
1299 Pennsylvania Ave, Suite 1175
Washington, DC, 20008

ⁱ <https://www.commonwealthfund.org/publications/journal-article/2018/oct/fragmented-care-chronic-conditions-overuse-hospital>