



This response to HHS's NPRM comes from two Michigan moms who are in the process of establishing an organization called HIPAA For Caregivers. We are dedicated to improving outcomes for caregivers and their loved ones with mental health conditions. We accomplish this through educating caregivers so that they understand HIPAA and can thus advocate effectively for their loved ones who experience mental health crises.

Our answers to specific **Requests for Comments** can be found a few paragraphs below, in the section headed with that phrase.

In general, we ask that HHS OCR optimize the final changes in HIPAA to enhance compassionate communication:

- Establish the language that decreases barriers for practitioners – “good faith belief” and “serious and reasonably foreseeable threat.”
- Expand the abilities of health care professionals to talk with caregivers, even without permission from the patients, any time they believe it is in the best interest of the patient.
- Incorporate language that clearly includes caregivers as part of the care coordination team, giving them access to treatment information just like other members of that team.

### **Need for compassionate communication between caregivers and health care providers**

Our mission is driven by our own personal experiences with the mental health care system. We know the hopelessness and frustration created when caregivers are blocked from communicating with health care providers, both during and after their loved one's mental health crisis, as a result of excessively strict interpretations of the HIPAA Privacy Rule. We have also seen the immense benefits derived by both family and patient when doctors take the most generous, least fear-driven view of HIPAA - actively listening to caregivers, effectively reacting to input, and appropriately sharing information about the patient with caregivers.

*It is so common for a patient, due to mental illness or substance use, to **not** want a caregiver involved in their health care. However, the value that would come if that caregiver were involved in the conversation is immense. Caregivers are stressing and hurting while they strive, uninformed, to help their loved ones. Even though they are giving far more of themselves than any other entity involved with the patient, they are being withheld from the conversation that could vastly improve the health outcomes of both the patient and the family.*

For these reasons, HIPAA for Caregivers also advocates for improvements in HIPAA text and/or interpretation, with a focus on compassionate communication between providers and patient's caregivers in the case of patients experiencing serious mental illness.



## Responses to specific “Requests for Comments”

HIPAA for Caregivers presents specific answers to the Request for Comments from Section E (3a, 3c, and 3f) and Section F (3a, 3c, and 3e).

### Section E

- a. The proposal in this section would improve care coordination and case management for a significant fraction of the patients in the United States experiencing mental illness *if* HHS OCR **specifically lists caregivers as members of the third parties** named in the proposed changes. This is because “Approximately 45% of mental health caregivers live with the care recipient, and nearly half of them report that the recipient is financially dependent upon them,” according to NAMI’s Circle of Care Report ([https://www.caregiving.org/wp-content/uploads/2020/05/CircleOfCareReport\\_0318\\_FINAL.pdf](https://www.caregiving.org/wp-content/uploads/2020/05/CircleOfCareReport_0318_FINAL.pdf)). Unfortunately, at the present time, caregivers of adults with mental illness are rarely able to talk with the care team without their loved one’s permission. This can be true even if their loved one’s doctors believe it would improve the patient’s chances of recovery.

Listed below are the logical supports from the NPRM itself for including and caregivers in the list of third parties allowed to receive PHI:

1. The Executive Summary of the Proposed Modifications notes three times, on page 6449 of the NPRM, that caregivers are part of care coordination and case management. The first instance is with regard to the view of the Department - “Although neither care coordination nor case management has a precise, commonly agreed upon definition, both refer broadly to a set of activities aimed at promoting cooperation among members of an individual’s health care delivery team, including **family members, caregivers**, and community based organizations.” The second instance is a quote from the Centers for Medicare & Medicaid Services (CMS), which notes “**family support**” as part of coordination of care. The third instance is the National Quality Forum’s definition of care coordination, which includes, “effective communication among health care providers, patients, **and caregivers**...”.
2. The new, proposed language is said to “permit covered entities to disclose PHI to social services, 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...” (p. 6476). That paragraph continues, “the third party may be providing health-related social services or other supported services – e.g. **food or sheltered housing** needed to address health risks.” By logical extension, therefore, caregivers that provide food, shelter, or financial support should be considered “third parties.”



By specifically naming caregivers among the third parties, HHS would be self-consistent within the text of the NPRM. Given the history of HIPAA, it seems likely that health care providers will not disclose PHI to caregivers, as third parties in coordination, unless HHS is clear about giving them permission to do so.

- c. As noted in response (a), barriers to disclosure of PHI to caregivers will only be removed for caregivers if HHS specifically names them as being one of the eligible third parties. We believe this change would improve care coordination and case management for a significant fraction of patients.
- f. Yes – the Department should specify the types of organizational entities to be included as recipients of PHI in this express permission in regulation text. Specifically, caregivers and carepartners should be included among the organizational entities, for reasons explained in response (a).

#### Section F

- a. We cannot imagine that a change in text to “good faith belief” would discourage individuals from seeking care.
- c. Yes - 45 CFR 164.501 (b)(3) should go further, along with any other portions of HIPAA necessary to make it consistent throughout, and be revised to permit a covered entity to disclose the PHI of an individual who has decision making capacity to the individual’s family member, friend, or other person involved in care, in a manner inconsistent with the individual’s known privacy preferences (including oral and written expressions), based on the covered entity’s good faith belief that the use or disclosure is in the individual’s best interests. Moreover, the changes should go further yet – they should express that the expectation is that health care providers **should** communicate with caregivers under that circumstance.
- e. We cannot imagine that a change to “serious and reasonably foreseeable threat” would discourage individuals from seeking care.