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Submitted Via Federal eRulemaking Portal at www.regulations.gov

U.S. Department of Health and Human Service
Office for Civil Rights
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, Docket No. HHS-OCR-0945-AA00

To Whom It May Concern:

The American Civil Liberties Union (ACLU) and the Bazelon Center for Mental Health Law submit these comments to express our support for the privacy protections contained in the Health Insurance Portability and Accountability Act of 1996 (HIPAA), together with the implementing regulations found at 45 C.F.R. Parts 160 and 164 (HIPAA Rules). We urge the Department of Health and Human Services (HHS), Office of Civil Rights (OCR), not to modify the existing rules in ways that would weaken their important privacy protections.

For nearly 100 years, the ACLU has been our nation's guardian of liberty, working in courts, legislatures, and communities to defend and preserve the individual rights and liberties that the Constitution and the laws of the United States guarantee to all people in this country. With more than three million members, activists, and supporters, the ACLU is a nationwide organization that fights tirelessly in all 50 states, Puerto Rico, and Washington, D.C. for the principle that every individual's rights must be protected equally under the law, regardless of race, religion, gender, sexual orientation, gender identity or expression, disability, national origin, or record of arrest or conviction. The ACLU's Disability Rights Program envisions a society in which discrimination against people with disabilities no longer exists, and in which people with disabilities are valued, integrated members of the community, and have jobs, homes, education, health care, and families.

Founded in 1972 as the Mental Health Law Project, the Bazelon Center for Mental Health Law is a national non-profit legal advocacy organization advancing the rights of individuals with mental disabilities in all aspects of life, including health care, education, employment, housing, community living, parental and family rights, voting, and other areas. Through litigation and policy advocacy, the Center advocates for equal opportunities for people with mental disabilities.

The HIPAA Rules Balance Privacy and the Need to Share Information, and Do Not Impose Unnecessary Burdens.

In its Request for Information, HHS seeks public input on “ways to modify the HIPAA Rules to remove regulatory obstacles and decrease regulatory burdens” to facilitate health care coordination and treatment. 83 Fed. Reg. 64302, 64309 (Dec. 14, 2018). This is the wrong approach. The HIPAA Rules already contain the flexibility to permit communications between health care providers and with family members. But misunderstanding or misinterpretations of HIPAA have led to calls for its reform. Agency efforts would be better spent in providing more information and education as to the flexibility and constraints of the Rules, rather than to undertake revisions.

Moreover, the right to medical privacy is a cornerstone of effective health care treatment. For these reasons, the ACLU and the Bazelon Center oppose any changes to HIPAA that would weaken its existing privacy protections.

The HIPAA Rules have been in place for more than 15 years and strike an appropriate balance. The Rules protect individual privacy while taking into account the needs of providers and caregivers. As the RFI makes clear, under the existing Rules, a health care provider already may disclose protected health information to another health care provider as needed for treatment. 83 Fed. Reg. 64302 (citing 45 C.F.R. §§ 164.501, 164.502(a)(1)(ii), 164.506). And a health care provider already may disclose protected health information to another, non-HIPAA-covered service provider as needed for the coordination and management of treatment. *Id.* (citing 45 C.F.R. §§ 164.501, 164.502(b)(2)(i)); *see also* U.S. Department of Health & Human Services, Health Information Privacy, FAQ 3008, at <https://www.hhs.gov/hipaa/for-professionals/faq/3008/does-hipaa-permit-health-care-providers-share-phi-individual-mental-illness-third-party-not-health-care-provider-continuity-care-purposes/index.html>.

Similarly, the HIPAA Rules already permit family, friends, or others who are involved in the patient’s care to receive protected health information that they need to know about the patient’s care under appropriate circumstances, including: with the patient’s permission; when the patient has been given the opportunity to object but does not; when a person poses a danger that could be averted by disclosure, in emergency circumstances, and when a person lacks the capacity to consent or object to disclosure. *See* U.S. Department of Health & Human Services, Health Information Privacy, Information Related to Mental and Behavioral Health, including Opioid Overdose, Decision Chart, at <https://www.hhs.gov/sites/default/files/families-hipaa-decision-tree-adult-patients.pdf>. The patient may also appoint a personal representative who can receive medical information being used by the provider. *Id.*

One of the suggested changes to HIPAA is that covered providers would be *required* to share protected health information upon receiving a request from another covered provider. Such a change would severely interfere with provider-patient relationships that are critical to good care because it would undermine the ability of providers to respect their patients’ wishes to keep medical information private.

There is no basis for the suggestion in the RFI that the patient privacy protections contained in the Rules should be weakened. The Administrative Procedures Act (APA) requires a federal agency conducting a notice-and-comment rulemaking to “examine the relevant data and articulate a satisfactory explanation for its action including a “rational connection between the

facts found and the choice made.” *Motor Veh. Mfrs. Ass'n v. State Farm Ins.*, 463 U.S. 29, 43 (1983) (citing *Burlington Truck Lines, Inc. v. United States*, 371 U.S. 156, 168 (1962)). Moreover, there is a presumption “against changes in current policy that are not justified by the rulemaking record.” *Id.* at 42. The citation to “anecdotal evidence,” *see* 83 Fed. Reg. 64306, is wholly insufficient for the broad changes suggested. Instead, the privacy protections in the Rules should be maintained.

Weakening Medical Privacy Rights for Individuals Under HIPAA Would Deter People from Seeking Treatment and Cause Predictable Harms.

The right to medical privacy is essential to an individual’s trust in and relationship with their health care providers, and their commitment to treatment. Changing the HIPAA Rules to weaken individual medical privacy rights would deter and undermine treatment, contrary to the purposes cited in the RFI.

This is particularly true for people with mental health disabilities, substance use disorders, HIV, Hepatitis C, and other conditions, treatments, histories, and statuses that are associated with social stigma and discrimination. For good reasons, an individual who is participating in treatment may not want private protected health information disclosed to other health care providers or other social services providers, or to involved friends and family members. For example, disclosing information about a mental health condition or substance use disorder, or information that was shared in confidence for purposes of the treatment of that condition or disorder, with a family member without the person’s consent may in some circumstances damage important relationships, hinder treatment, or enable the continuation of abuse by a caregiver. It is well established that individuals who are no longer sure that their privacy is protected are often deterred from accessing or continuing treatment, or omit important information in the course of treatment in order to protect their privacy.¹

Some hypotheticals illustrate these problems:

“Raul” has a history of Hepatitis C that was treated successfully with Interferon years earlier. He moves to a small town and makes an appointment to see a new primary care doctor. He doesn’t want the new doctor to know about his history of Hepatitis C because of the stigma. He worries that the new doctor will send out a request for his prior medical records. Raul wants to tell his old doctor not to send the records about Hepatitis C. Without privacy protections, he decides he will not risk going to the doctor. As a result, Raul’s high blood pressure goes undetected.

“Brian” has bipolar disorder and is living with his parents, who are involved in his mental health care and treatment. He is also receiving MAT (medication assisted treatment) for substance use disorder. His parents oppose MAT because they consider it another form of drug addiction. Even though his parents help him with his other medications and with rides to his psychiatrist, Brian does not want them to know about the MAT. He fears that

¹ *See, e.g.,* Janlori Goldman and Zoe Hudson, Georgetown University Health Privacy Project, *Promoting Health/Protecting Privacy: A Primer* (Jan. 1999), available at <https://www.chcf.org/wp-content/uploads/2017/12/PDF-conprimer.pdf>.

they would insist that he stop using MAT or that they would kick him out of the house and he would be homeless. Under the proposed HIPAA changes, his psychiatrist reveals to his parents that Brian is using MAT, they kick him out of the house, and Brian becomes homeless, misses his MAT medication, and relapses into illegal drug use.

“Jinny” has a history of drug addiction and is living in clean and sober housing. She is also in treatment for PTSD and GAD, and has a history of psychiatric hospitalizations. The director of the sober living house has expressed bias against people with psychiatric conditions, and has stated that he does not want people with those problems in his program. Jinny requests that her therapist keep the information about her psychiatric conditions private. Under the proposed HIPAA changes, the therapist sends information about Jinny’s psychiatric conditions, and the sober living house kicks her out. Though this is illegal, Jinny has no ability to find an attorney to represent her, given her homelessness and medical conditions.

“Carla” is seeing a therapist for treatment of mental health issues including post-traumatic stress disorder stemming from abuse that she has suffered. Her husband, at whose hands she has experienced abuse, has warned her not to seek help. Without the certainty that her therapist will keep her treatment confidential from her husband or other family members, and knowing that she will face retaliation if her husband finds out, Carla stops her treatment.

Congress Considered and Rejected the Types of Changes Suggested by the Request for Information with Respect to Individuals with Serious Mental Illness

HHS lacks authority to promulgate changes to HIPAA that would effectively provide lower privacy protections for individuals with serious mental illness and/or substance use disorders because in enacting HIPAA, Congress did not authorize differential privacy protections based on diagnosis. Moreover, Congress actually *rejected* legislative efforts to lower privacy protections for individuals with serious mental illness. Early versions of the Helping Families in Mental Health Crisis Act, which passed as part of the 21st Century Cures Act, would have reduced privacy protections for individuals with serious mental illness by broadening the circumstances under which disclosure of protected health information was permitted to responsible caregivers for such individuals.²

Congress rejected the provisions weakening the privacy rights of individuals with serious mental illness, and indicated that communication problems between providers and caregivers for people with serious mental illness reflect “confusion in the health care community” concerning permitted disclosures and uses under HIPAA.³ Indeed, the hearings held in connection with the Helping Families in Mental Health Crisis Act demonstrated that there is widespread misunderstanding of the exceptions that HIPAA already provides to privacy protections.

² See, e.g., HR. 2646, Title IV: HIPAA and FERPA Caregivers (114th Congress).

³ 21st Century Cures Act, Pub. L. No. 114-255, § 11001(a)(9).

Multiple witnesses testified that HIPAA was invoked to prevent disclosure of information in circumstances where the law clearly permitted disclosure.⁴

Congress directed HHS OCR to “ensure that health care providers, professionals, patients and their families, and others involved in mental or substance use disorder treatment have adequate, accessible, and easily comprehensible resources relating to appropriate uses and disclosures of protected health information” under HIPAA, and to issue guidance to clarify permitted uses or disclosures of protected health information for purposes of:

- (A) communicating with a family member of the patient, caregiver of the patient, or other individual, to the extent that such family member, caregiver, or individual is involved in the care of the patient;
- (B) in the case that the patient is an adult, communicating with a family member of the patient, caregiver of the patient, or other individual involved in the care of the patient;
- (C) in the case that the patient is a minor, communicating with the parent or caregiver of the patient;
- (D) involving the family members or caregivers of the patient, or others involved in the patient’s care or care plan, including facilitating treatment and medication adherence;
- (E) listening to the patient, or receiving information with respect to the patient from the family or caregiver of the patient;
- (F) communicating with family members of the patient, caregivers of the patient, law enforcement, or others when the patient presents a serious and imminent threat of harm to self or others; and
- (G) communicating to law enforcement and family members or caregivers of the patient about the admission of the patient to receive care at, or the release of a patient from, a facility for an emergency psychiatric hold or involuntary treatment.⁵

HHS did promulgate guidance addressing all of those issues, as well as guidance addressing similar issues for individuals with substance use disorders, to clarify what uses and disclosures are permitted.

Congress also directed OCR to disseminate model training programs and materials to clarify these issues.⁶ OCR’s efforts would be best spent disseminating information and training to

⁴ For example, one witness testified that a psychiatric hospital invoked HIPAA in declining to discuss his son’s mental health issues with him but he later discovered that the son had signed a release authorizing the hospital to speak with his parents. Another witness testified that she believed (incorrectly) that HIPAA precluded her from informing family members that a person was lying unconscious in the emergency room.

⁵ *Id.* § 11003.

⁶ *Id.* § 11004.

educate providers, family members, and individuals with serious mental illness and/or substance use disorders about what HIPAA requires, rather than trying to modify HIPAA regulations in a manner that defies Congressional intent.

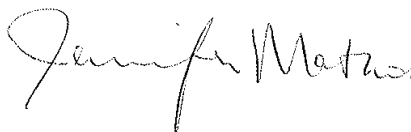
The ACLU and Bazelon Center urge OCR to maintain the right of individuals to control their own medical information. Allowing providers and caretakers more access to an individual's private protected medical information beyond the existing rules is unsupported and would cause predictable harms. We oppose any weakening of these critical protections.

If you have any questions or comments, please contact Mike Garvey at mgarvey@aclu.org or Jennifer Mathis at jenniferm@bazelon.org.

Sincerely,



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