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Robinsue Frohboese
Acting Director
Office for Civil Rights
U.S. Department of Health and Human Services
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 (RIN 0945-AA00)

Dear Acting Director Frohboese:

The Center for Reproductive Rights submits these comments in response to the Notice of Proposed Rulemaking (NPRM, or the Proposed Rule) on Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement, as published by the Department of Health and Human Services (HHS)'s Office of Civil Rights (OCR) in the Federal Register on Thursday, January 21, 2021.¹ The Proposed Rule would modify the Standards for the Privacy of Individually Identifiable Health Information (Privacy Rule) under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) and the Health Information Technology for Economic and Clinical Health Act of 2009 (HITECH Act).

The Center for Reproductive Rights is a global human rights organization that uses the power of the law to advance reproductive rights as fundamental human rights that governments around the world are obligated to protect, respect, and fulfill. Reproductive freedom lies at the heart of the promise of human dignity, self-determination, and equality embodied in both the U.S. Constitution and the Universal Declaration of Human Rights. Federal laws like HIPAA provide critical protections for individuals exercising their reproductive rights by regulating the privacy and security of information and ensuring patient-centered decision-making and informed consent.

We recognize the importance of OCR considering changes that may be needed to better facilitate sharing of protected health information (PHI) with appropriate privacy protections. However, we write to share our concerns regarding two provisions in the NPRM that could erode patients' rights to privacy and confidential care, especially minors and people seeking stigmatized care. We urge OCR not to proceed with finalizing these provisions, and we encourage the agency to first pursue educational outreach and other implementation measures

¹ Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement, 86 Fed. Reg. 6446 (proposed Jan. 21, 2021).

that could remedy the anecdotal concerns the agency has heard before moving forward with rulemaking on these provisions. We further urge that any final rule modifying HIPAA prioritize protecting individuals' control over their own treatment and over any sharing of their PHI. Safeguarding patients' privacy rights and autonomy in this regard is essential to protecting the right to access health care with dignity, free from discrimination, and without other significant barriers.

Encouraging Disclosures of PHI when Needed to Help Individuals Experiencing Substance Use Disorder (Including Opioid Use Disorder), Serious Mental Illness, and in Emergency Circumstances (45 CFR 164.502 and 164.510-514)

Changing "professional judgement" to "good faith"

The Department proposes to amend five provisions of the Privacy Rule to replace "exercise of professional judgment" with "good faith belief" as the standard pursuant to which covered entities would be permitted to make certain uses and disclosures in the best interests of individuals. The Department explains the proposed "good faith" standard as deliberately inviting much more expansive sharing of private information with family members and other third parties, despite acknowledging "prior comments expressing concern that a good faith standard offers individuals less privacy protection."² The Department also proposes a presumption that a covered entity has complied with the good faith requirement, absent evidence that the covered entity acted in bad faith. We urge the Department not to pursue these proposed changes and instead to maintain the "professional judgment" standard.

Insufficient Evidence to Justify the Change in Policy

The Privacy Rule already permits covered entities to share PHI with family, friends, or caregivers in certain circumstances and the NPRM lacks sufficient evidence justifying the proposed change. Anecdotal reports of providers being hesitant to share PHI in some instances is an insufficient basis for proposing the change to a "good faith" standard (with a presumption of compliance) that could severely compromise patient privacy as described below.

Changing to the "Good Faith" Standard Would Harm Patients

A "good faith" standard is too permissive and would significantly weaken confidentiality protections. We are especially concerned about the implications of such a change for young people, or for any person seeking care for "sensitive" health services such as reproductive health care, LGBTQ-affirming care, mental health care, or substance use disorder treatment. Often young people or people seeking these types of care experience shame or stigma from their family members, who may try to deny them access to or otherwise interfere with their care. Even something as seemingly simple as sharing the fact of an upcoming appointment with a family member could seriously compromise the patient's confidentiality or safety, if for example, the type of provider (i.e., a gynecologist)

² 86 Fed. Reg. at 6480.

reveals information about the nature or type of services that someone may be seeking.

Moreover, young people or people seeking sensitive or stigmatized forms of care are often especially vulnerable to abuse by family members or caregivers, and sharing PHI in those circumstances can cause significant harm. While the Department says that it “assumes that health care providers would incorporate relevant concerns about an individual’s risk of abuse as a key factor in whether a disclosure of PHI is in an individual’s best interest” and that “disclosures to suspected abusers are not in the best interests of individuals,”³ these assumptions and assurances are insufficient. Covered entities may not be aware that individuals are estranged from their families, or may not be aware or able to foresee that the disclosure of PHI could lead to the individual being estranged or otherwise facing harm from their families. For example, research suggests that a top cause for homelessness among LGBT youth—who are significantly overrepresented in homeless populations compared with their proportion of the U.S. population—is family rejection based on their sexual orientation or gender identity.⁴ Increasing the risk of disclosures that could harm these young people could compound other existing barriers to safe, supportive services they experience. HIPAA privacy protections should work to safeguard patient-centered decision-making, in recognition that each patient knows their situation best and should be able to control sharing of their PHI. By safeguarding patients’ autonomy, these protections can help prevent significant risks to patients’ rights and safety.

In addition, we are concerned about the chilling effect that a permissive standard will have, since concerns about family members being able to access PHI can deter people from seeking the care they need, especially with respect to sensitive care. Federal protections against disclosure of health information can help people feel comfortable in accessing health care by ensuring they can control and direct their sharing of their PHI and by providing safeguards for disclosures in exceptional circumstances already provided for in the Privacy Rule. These protections make it possible for individuals to establish a trusting relationship with their providers.

We are also very concerned by the NPRM’s proposal that there will be a presumption that a covered entity has complied with the good faith requirement, absent evidence that the covered entity acted in bad faith. This presumption likely renders the “good faith” standard largely unenforceable, so there will be few, if any, mechanisms for remedying when disclosure have been made in violation of HIPAA. Without sufficient guardrails to protect patient confidentiality, this presumption is insufficient protection.

³ 86 Fed. Reg. at 6481.

⁴ Homelessness & Housing, Youth.gov, <https://youth.gov/youth-topics/lgbtq-youth/homelessness> (last accessed May 5, 2021).

Lastly, the Department specifically asks whether 45 CFR 164.510(b)(3) should 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, in any situations outside of an emergency circumstance.” We do not believe - outside of an emergency - that there is a situation where the totality of the facts or circumstances should outweigh an individual’s express preferences.

We urge OCR to consider ways that confidentiality protections for minors and others seeking sensitive health services could be strengthened in order to encourage them to seek care and continue treatments, not promulgate rulemakings that would undermine their privacy rights and potentially dissuade them from seeking care.

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 (45 CFR 164.506)

Whether the proposal to create an express permission to disclose PHI to certain third parties for individual level treatment and health care operations poses any particular risks for individuals

The existing Privacy Rule already permits covered entities to disclose PHI to third parties as needed for treatment and case management coordination. While we support efforts to improve information sharing and facilitating treatment, we strongly believe patients must be at the center of decisions related to care planning and coordination, including discussing all referrals with individuals before they are made. 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. Instead of creating an express permission to disclose PHI to certain third parties, we recommend that OCR provide guidance and best practices to covered entities related to conversations with patients about information sharing, including who the information will be shared with; what information will be shared; and the intended purpose of the disclosure.

Without having these conversations, unintended consequences are inevitable. For example, the NPRM explains that the proposal to create an express permission to disclose PHI to certain third parties would allow for disclosures such as the following: “a covered entity could disclose the PHI of a senior individual experiencing chronic illness to a senior center attended by the individual to check on his or her health periodically, and to ask the senior center to give reminders about effective disease self-management.”⁵ It is not difficult to imagine that this

⁵ 86 Fed. Reg. at 6476.

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kind of example could lead to covered entities interpreting the proposed modification as greenlighting more proactive disclosures of PHI with third parties without the patient's authorization. While such sharing may benefit some patients, it could harm others; for example, a covered entity disclosing the PHI of a minor patient receiving reproductive health services to a community-based organization opposed to minors having access to such care could endanger their privacy and lead to unwanted interference in their ability to access care.

Even disclosures that may be routine could have adverse effects for some individuals depending on the information and the entities with which it is shared. For example, disclosures for the purpose of assisting individuals with transportation to medical appointments could potentially reveal information about the individual's gender identity, sexual orientation, pregnancy status, or other characteristics that lead to the individual experiencing repercussions, for example from a church or faith-based organization. The identity of the provider, like a women's health center for example, in and of itself could cause problems if the third party is not aligned with the provider's mission, values, and services provided. As a result, an individual, just by virtue of being a patient of that provider, could face discrimination or other consequences by the third party. Therefore, we urge OCR to consider all possible scenarios and ensure that there are sufficient guardrails to protect confidentiality in such circumstances.

The individuals who could face the most harm from these proposed changes already face disproportionate barriers to accessing health care, so any harmful effects of the changes would amplify difficulties in accessing care for these individuals

If young people cannot feel secure that health care services and PHI will be confidential, they may delay, forgo, or even be denied needed care by parents, guardians, or others. That is why the American Medical Association,⁶ the Society of Adolescent Medicine,⁷ and the American Academy of Family Physicians⁸ have stated it is essential that adolescents have independent access to confidential health care, and the Centers for Disease Control and Prevention⁹ has emphasized the importance of guaranteeing independent access and confidentiality

⁶ AMERICAN MEDICAL ASSOCIATION, OPINION 5.055 – CONFIDENTIAL CARE FOR MINORS (Nov. 2014), <https://journalofethics.ama-assn.org/sites/journalofethics.ama-assn.org/files/2018-05/coet1-1411.pdf>.

⁷ Carol Ford, Abigail English & Garry Sigman, *Confidential Healthcare for Adolescents: Position Paper of the Society of Adolescent Medicine*, 35 J. ADOLESCENT HEALTH 160 (Aug. 1, 2004), [https://www.jahonline.org/article/S1054-139X\(04\)00086-2/fulltext](https://www.jahonline.org/article/S1054-139X(04)00086-2/fulltext).

⁸ AMERICAN ACADEMY OF FAMILY PHYSICIANS: POLICIES, *Adolescents Healthcare, Confidentiality*, <https://www.aafp.org/about/policies/all/adolescent-confidentiality.html> (last visited May 5, 2021).

⁹ DIVISION OF REPRODUCTIVE HEALTH, CENTERS FOR DISEASE CONTROL AND PREVENTION, *A Teen-Friendly Reproductive Health Visit*, <http://www.cdc.gov/teenpregnancy/health-care-providers/teen-friendly-health-visit.htm> (last visited May 5, 2021).

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protections when developing teen-friendly reproductive health care. When young people are assured of confidentiality in the provision of health services and any related communications, they are more likely to seek health services, disclose health risk behaviors to a clinician, and return for follow-up care.¹⁰ This is particularly true for sensitive health care services that carry societal stigmas, such as sexual, reproductive, gender-affirming, mental health and substance abuse services.

Conclusion

We urge OCR not to proceed with finalizing the above provisions. We also urge OCR to ensure that any final rule align with this administration's healthcare priorities and commitment to safeguarding and advancing access to high quality, confidential care, including reproductive health care and other sensitive health services.

We appreciate the opportunity to comment on this NPRM. If you require any additional information about the issues raised in this letter, please contact Katherine Gillespie, Acting Director, Federal Policy and Advocacy, at kgillespie@reprorights.org.

Signed,
The Center for Reproductive Rights

¹⁰ Abigail English & Carol A. Ford, *The HIPAA Privacy Rule and Adolescents: Legal Questions and Clinical Challenges*, 36 PERSPECTIVES ON SEXUAL AND REPROD. HEALTH 80 (Apr. 2004), <https://www.guttmacher.org/journals/psrh/2004/hipaa-privacy-rule-and-adolescents-legal-questions-and-clinical-challenges>.