MEDICARE RIGHTS CENTER
Getting Medicare right

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May 6, 2021

Robinsue Frohboese
Acting Director
Office for Civil Rights
U.S. Department of Health and 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 Acting Director Frohboese:

The Medicare Rights Center (Medicare Rights) appreciates this opportunity to comment on the Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement. Medicare Rights is a national, nonprofit organization that works to ensure access to affordable health care for older adults and people with disabilities through counseling and advocacy, educational programs, and public policy initiatives. Each year, Medicare Rights provides services and resources to nearly three million people with Medicare, family caregivers, and professionals.

General comments

The Office for Civil Rights (OCR) has proposed to modify certain privacy provisions of the implementing regulations (Privacy Rule) for the Health Insurance Portability and Accountability Act of 1996 (HIPAA). For consumers, caregivers, and families across the country, HIPAA and the Privacy Rule are a fundamental protection against misuse or improper disclosure of private information.

At Medicare Rights, we strongly support proposed changes that will enhance access to health records for individuals. Individuals ideally need information within hours or days, particularly for coordination

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and continuity of care. Long waits impede their ability to get a second opinion, to start treatment, to qualify for an experimental drug, or to avoid an allergic reaction or other contraindication.

The notice of proposed rulemaking (NPRM) makes clear that covered entities may misunderstand current rules, creating burdens and barriers for consumers.[1] While some of the NPRM's proposals are to improve access to information, others are to mitigate misunderstandings or misapplications of the Privacy Rule. Many of the issues flagged in this NPRM appear to be more a function of inadequate implementation, education, and training than imprecision or a lack of clarity within the regulatory language. Covered entities may not properly operationalize any rule, but if that failure is caused by a lack of clear guidance for implementation, an educational or training gap, or even by gaming the system, subsequent changes in the rule to account for those behaviors will simply create new pockets of misunderstanding or misapplication.

Some proposals in this NPRM relax privacy protections and standards. Providing appropriate care and addressing adverse social determinants of health often require robust information sharing, but it must not come at the expense of patient privacy and choice. We urge very careful attention to ways in which rule changes may expose private information to misuse and abuse.

Individual Right of Access

OCR proposes to shorten the timeframe for covered entities to facilitate individual access to personal health information to less than 30 days. We strongly support this proposal. We believe this will motivate more rapid responses from covered entities and encourage them to seek technology solutions that better facilitate the provision of digital copies. For data generated and stored electronically in a standardized format, access should generally be close to real-time. Covered entities should make this data available as soon as practicable.

Likewise, we support the provisions to make it easier for people to access their records in a mutually convenient and respectful manner. This includes providing additional opportunities to inspect records in person, to ensure any updates or corrections are made, and to explicitly permit patients to take notes, videos, and photographs using personal resources. It is important to preserve non-technological means for access and copies of personal health information (PHI) for individuals without the necessary devices, internet connections, or digital skills.

We support prohibiting covered entities from implementing unreasonable identity verification requirements, such as requiring a request to be notarized, or requiring an individual to request records in person. We also strongly support the proposals to reduce and clarify applicable costs associated with accessing patient records, and to require covered entities to provide advance notice of approximate fees for requested copies of PHI.

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[1] *See, e.g.*, 86 Fed. Reg. 6446, 6475.

OCR asks if covered entities should be prohibited from charging fees for copies of PHI when requested by certain categories of individuals or when the copies are directed to particular types of entities. We urge OCR to include such a prohibition which would ensure people with few resources or whose information is going to research organizations would have better access to their information.

Similarly, OCR asks if covered entities should be prohibited from denying requests to exercise the right of access to copies of PHI when the individual is unable to pay the access fee. Again, we urge OCR to include such a prohibition to ensure that an individual's ability to pay does not impede their exercise of their rights.

Creating an Exception to the "Minimum Necessary" Standard for Individual Level Care Coordination and Case Management Uses and Disclosures

OCR proposes to relieve covered entities of the requirement to disclose only the "minimum necessary" information to a health plan or covered health care provider for care coordination and case management activities with respect to an individual, regardless of whether such activities constitute treatment or health care operations. We strongly oppose this proposal. It is important for covered entities to be required to consider what information is reasonably needed for their purpose before making a request, use, or disclosure. The outlined exception would eliminate a clear boundary, leading covered entities to disclose entire patient records to each other, when convenient, without effective limit. Information must not be shared casually or more broadly than necessary, and the rules must not be for the convenience of the covered entities at the expense of the privacy of the individual's information.

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

OCR notes that covered entities already have the ability to disclose PHI about an individual to a third party that is part of the broader health treatment plan or participating in the coordination of care for the individual, including disclosures to home- and community-based services providers.[2] OCR has, it notes, put out guidance on the topic, but also notes that some covered entities appear to overlook the guidance: "Some covered entities may not be aware that the Privacy Rule contemplates disclosures of PHI to third party organizations without authorization for care coordination and case management, including when required by law."[3]

As a result, OCR proposes to create an express permission to disclose PHI to certain third parties for individual level treatment and health care operations. Although this kind of PHI disclosure to certain third parties is already allowable and efforts to clarify may create unintended consequences and greater laxity, we cautiously support this proposal. However, we urge additional safeguards. Disclosure of PHI to a non-health care provider without a patient's authorization continues to present important challenges

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[2] *Id.* at 6475.

[3] *Id.*

and potential unintended consequences that must be thoughtfully considered. Not only does the disclosure increase the risk that PHI will be exposed, there could also be a negative impact on utilization of health care services if consumers lack assurances of confidentiality about where and with whom their information will be shared. And PHI that includes information about stigmatized conditions or treatments may trigger punitive or discriminatory behaviors. For example, a Substance Use Disorder diagnosis could trigger child welfare investigations or denial of housing.

We urge OCR to consider mitigating strategies to better support consumers and entities. Primary among them should be the expectation that covered entities will fully discuss information sharing with patients, including which entities would receive the information, what information will be shared, and what options the patient may have if they do not want their information to be shared. We also urge the creation of incentives to increase technical capabilities around data segmentation to allow individuals to flag certain parts of their record as not to be shared without explicit permission; dissemination of best practices to give both covered and non-covered entities the opportunity to view examples of successful information sharing with third parties; educational materials tailored for social service providers to better understand the basic tenets of HIPAA and PHI privacy; and greater and improved education to health care providers, patients, and caregivers regarding the provisions of HIPAA that permit uses and disclosures of PHI.

Educational materials and training should be developed and targeted in ways that are useful for an array of stakeholders, including providers, patients, caregivers, and other social services or community-based organizations. Information should be accessible and understandable by all, including people with limited English proficiency and users with disabilities. OCR should have a strong infrastructure in place that is able to quickly and thoroughly address questions and concerns from patients and families. Outreach and education should also focus on how state and other federal laws interact with HIPAA, including those that have even stronger privacy protections.

In educational and guidance materials, we encourage OCR to provide examples of types of organizational entities to be included or excluded in any express permission and to evaluate potential exemplar entities through a health equity lens. For example, disclosures to any law enforcement entity that may be part of a multi-disciplinary care team may deter patients, particularly patients of color and immigrants, from seeking needed care out of legitimate fear of entrenched and systemic racism and punitive approaches.

OCR seeks comment on whether the rule should require, as a condition of the disclosure, that the parties put in place an agreement that describes and/or limits the uses and further disclosures allowed by the third-party recipients. We support the inclusion of such a limitation to protect the privacy and confidentiality of data and to better preserve patient trust and willingness to engage with the health care and social support systems.

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

Professional judgment and good faith belief

OCR 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. We strongly oppose this change.

The proposed “good faith” standard invites much more expansive sharing of private information with family members and other third parties, and would significantly weaken confidentiality protections. While OCR 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,” these assumptions and assurances are insufficient.[4]

The agency illustrates this potential shift in the text, noting that it would allow front desk staff to make a good faith judgment about whether to share information about an appointment with the patient’s family members.[5] But in describing what should go into a good faith belief, OCR states it “may be based on, for example, knowledge of the facts of the situation (including any prior expressed privacy preferences of the individual, such as those in an advance directive), or the representations of a person or persons who reasonably can be expected to have knowledge of relevant facts.”[6] Front desk staff do not—and should not—have access to relevant facts or information necessary to inform a good faith belief about whether or not a disclosure would be in someone’s best interest.

In addition, OCR proposes to adopt a presumption that a covered entity will have complied with the good faith requirement, absent evidence that the covered entity acted in bad faith. Such a presumption would render the “good faith” standard largely unenforceable, ensuring few, if any, remedies for disclosures made in violation of HIPAA. Without sufficient guardrails to protect patient confidentiality, this presumption is not appropriate.

Finally, OCR asks if disclosures should be made “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.”[7] We strongly oppose the ability to override an individual’s wishes and express preferences outside of an emergency.

Changing “serious and imminent” to “serious and reasonably foreseeable”

OCR proposes to amend the Privacy Rule to replace the “serious and imminent threat” standard with a “serious and reasonably foreseeable threat” standard in order to prevent situations in which covered

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[4] *Id.* at 6481.
[5] *Id.*
[6] *Id.*
[7] *Id.* at 6483.

entities decline to make disclosures they believe are needed to prevent harm due to concerns that their inability to determine the precise imminence of the threat may make them subject to HIPAA penalties for an impermissible use or disclosure. While we understand that OCR is seeking to prevent situations in which covered entities do not make disclosures they believe are needed, it would be no less difficult to determine whether a harm is “reasonably foreseeable.” Both standards are terms of art under the law, and require additional guidance or training to understand in context. Rather than alter the current standard, we encourage OCR to provide more information to covered entities on how to assess imminence in ways that appropriately balance the need to protect patient information against the importance of protecting others from harm.

We also have grave concerns about the equity of a “reasonableness” standard. Such a standard could invite more bias and prejudice into the determination about the risk of harm because it would be built upon specific cultural assumptions of what is reasonable rather than professional judgment. The potential for bias or inaccurate assumptions is especially great for people and communities of color or in the context of stigmatized care, such as mental health care or substance use disorder treatment. OCR does attempt to mitigate some of this bias in the narrative of the NPRM—noting, for example, that someone with a mental health condition is not more likely than anyone else to commit an act of violence[8]—but that sentiment is insufficient when weighed against cultural pressures and expectations that paint certain populations and communities as more dangerous.

Conclusion

Thank you again for this opportunity to provide comment. For further information, please contact Lindsey Copeland, Federal Policy Director at LCopeland@medicarerights.org or 202-637-0961 and Julie Carter, Senior Federal Policy Associate at JCarter@medicarerights.org or 202-637-0962.

Sincerely,

Fred Riccardi

Fred Riccardi
President
Medicare Rights Center

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[8] *Id.*