April 7, 2021

The Honorable Xavier Becerra  
Secretary  
Department of Health and Human Services  
200 Independence Avenue  
Washington, DC 20201

Re: HHS-OCR-0945-AA00 Proposed Modifications to the HIPAA Privacy Rule to Support, and Remove Barriers to, Coordinated Care and Individual Engagement

Dear Secretary Becerra:

AARP, on behalf of our nearly 38 million members and all older Americans nationwide, thanks you for the opportunity to comment on proposed modifications to the Health Insurance Protection and Accountability Act “privacy rule”. We support the Department’s efforts to update HIPAA regulations in light of technological advancements since the law’s creation roughly 25 years ago.

HIPAA protections remain invaluable for safeguarding personal health data and allowing individuals to maintain control over sensitive information about their health. Since HIPAA’s creation, though, the sources, types, and volume of data have grown exponentially. AARP agrees that revisions are necessary to keep pace with technological innovation and ensure our health system is able to deliver person- and family-centered care. Below, we comment on specific proposed changes impacting the individual and family-caregiver experience.

Definitions

AARP supports the use of clearly defined terms to avoid confusion among individuals and covered entities. In response to proposed definitions, we make the following recommendations to ensure all stakeholders have a shared understanding of specific terms and concepts.

Care coordination and case management – AARP recognizes it may be difficult to create singular definitions that encompass the totality of experience. We respect using a non-exhaustive list of examples which illustrates these terms, rather than a single definition. However, we urge you to articulate a unifying principle to make clear that all the examples place the consumer at the center of care. Moreover, we also suggest including examples of what care coordination and case management are not, so as to create boundaries and prevent wayward interpretations.

Electronic Health Record (EHR) – We approve of the proposed definition of EHR. In particular, we support specific reference to both “health” and “health-related” information as being protected. We note, though, that de-identified health and health-related information is not protected by HIPAA. The Office of Civil Rights must be able to hold covered entities accountable for fully de-identifying data by removing all 18 identifying elements in the HIPAA Safe Harbor.

- Names
- Geography/Location
- Dates
- Telephone numbers
- Fax numbers
- Email addresses
- Social Security numbers
- Medical record numbers
- Health plan beneficiary numbers
- Account numbers
Personal Health Application (App) – AARP is concerned that while the proposed definition absolves the covered health care entity of any responsibility for data the individual extracts and places onto an app, it does not necessarily place any responsibility on the new entity now hosting the data. The terms “managed”, “shared”, and “controlled” are not the equivalent of “possess”, “hold”, or “maintain”. An individual having the ability to access their own data on an app does not inherently prevent the app developer from accessing the data as well. Apps are becoming increasingly prevalent, and HHS has promoted their development and usage, such as by sponsoring events like Datapalooza. We see an unfortunate paradox in HHS encouraging consumers to take control of their own data, while the proposed definition would simultaneously remove privacy protections – and give consumers less control of their data – once they do. Responsibility and accountability should also be extended to app developers to avoid potential harm to consumers. For example, a covered entity could circumvent privacy rules by developing its own app and encouraging or mandating its use by its clients. Once the individual or family member removes data from the covered entity’s portal and puts it on the entity-developed app, privacy protections are removed, and individual’s data could be sold. Consumer health and health-related data must be private and protected regardless of where it is housed.

Strengthening the Access Right to Inspect and Obtain Copies of Protected Health Information

AARP strongly supports the proposal to extend the right of individuals to “inspect and obtain” a copy of their protected health information (PHI) to include the right of individuals to “take notes, videos, and photographs, and use other personal resources to view and capture PHI.” We urge you, though, to clearly state that this right applies to the individual’s designated caregiver and legally authorized representatives as well. Furthermore, we urge you to define the term “readily available”. This term presumably is intended to mean more than simply information that is on screen or in the hands of the provider during the health care interaction. “Readily available” should also apply to easily accessible documents in a file cabinet and to data that simply requires a few clicks or keystrokes to access in a matter of minutes.

Lastly, HHS requests comments on whether covered entities should be permitted to provide copies of PHI in lieu of in-person inspection in certain circumstances, such as the current public health emergency. AARP assumes this permission is for requests that are not made in person. If the individual and family-caregiver or representative is already physically present for care delivery, then there is no reason to delay in-person inspection of PHI. Likewise, if the individual is making a request for PHI while engaged in an audio-visual telehealth visit, and the covered entity has the technological capacity to share or show PHI (e.g. screen sharing), it is unnecessary to delay inspection and provide copies. For situations in which the individual or family-caregiver makes an advanced request to obtain or inspect PHI in person, AARP agrees that it is reasonable for copies to be provided to minimize contact. However, providing copies cannot be used as reason for delaying delivery or charging fees.
Modifying the Implementation Requirements for Requests for Access and Timely Action in Response to Requests to Access

AARP supports the proposal to expressly prohibit a covered entity from imposing unreasonable measures that create a barrier or unreasonable delay of an individual’s right to access. Requirements for information, multiple procedures or forms, or disparate points of contact all create barriers to access. The more steps required, the more time and energy that is unnecessarily expended. Additionally, we support and applaud the proposal to shorten the timeframe for when covered entities must provide copies of PHI. We agree that a request for PHI can be fulfilled in under 15 days, and that the current 30-day time limit is unnecessary and potentially harmful to consumers.

Addressing the Individual Access Right to Direct Copies of PHI to Third Parties

AARP supports the proposal to allow an individual to request PHI in writing, orally, or electronically. The current requirement that the request must be in writing and signed is unnecessary and creates a burden to access. We also support the proposed creation of a pathway whereby the individual’s health care provider or health plan can request the PHI, at the direction of the individual, from another provider. This will facilitate information coordination and alleviate the burden placed on consumers to request and transmit PHI between their health care providers.

Adjusting Permitted Fees for Access to PHI and ePHI and Notice of Access and Authorization Fees

AARP believes that individuals should have access to their health information and PHI readily and freely. There should be no limit to the number of times an individual or their family-caregiver can request to inspect PHI in person, nor should there be a fee charged for in-person inspection. Copies of PHI should be made available to individuals and their family-caregivers electronically at no cost. Given the significant amount of resources that the federal government has invested in meaningful use and to promote interoperability, there is no excuse for not offering the option of electronic access to PHI, such as through Blue Button, with appropriate security protections. In fact, we would urge that providers who do not offer an electronic option like Blue Button should not be able charge consumers for copies of their PHI at all. Conversely, for providers who do offer Blue Button, it may be appropriate to permit a nominal fee for making paper copies, but only to cover the costs associated with the task and devoid of any profit. A provider should only be able to charge for physical copies if the consumer also has the option for electronic copies. Furthermore, the charged fees should be documented and transparent. We therefore support the proposal to require covered entities to provide advance notice of approximate fees for copies of PHI.

More specifically, HHS asks whether the Privacy Rule should prohibit covered entities from charging fees for copies of PHI for certain categories of individuals (e.g. Medicaid beneficiaries) or certain types of entities (e.g. clinical research). Many individuals and their families do not have internet access or access to a computer or are limited physically or otherwise unable to download their PHI through a patient portal, and therefore must request physical copies of their PHI. AARP urges an exemption from any fees for people who do not have the option – due to income, physical ability, or technological barriers – of requesting copies of their PHI electronically.
Reducing Identity Verification Burden

AARP supports HHS’s proposal to prohibit a covered entity from imposing unreasonable identity verification measures on an individual or their personal representative. HHS raises the question of whether the covered entity holding the PHI can rely on the covered entity making the request for PHI to validate the identity of the individual, or must it independently validate the individual’s identity itself. That is to say, can one covered entity verify an individual’s identity to another covered entity? AARP believes that an individual’s identity does not need to be re-verified, so long as the requesting covered entity can document that the individual is aware the request for PHI is being made on their behalf.

Additionally, HHS asks if there should be different verification standards for an individual and for a personal representative. AARP maintains that individuals, authorized representatives, and family-caregivers should all have easy access to the individual’s protected health information. No additional burdens or barriers should be place on these individuals. The surest way to demonstrate that the personal representative is authorized to obtain the individual’s PHI is to have that person identified in the EHR or care management plan. Family caregivers in particular should be fully integrated into care delivery and, with the individual’s consent, have access to information.

Creating an Exception to the “Minimum Necessary” Standard

HHS proposes to add an express exception to the minimum necessary standard for the purposes of care coordination and case management. AARP is generally supportive of this exception, as we believe that it is reasonable for a covered entity to share a broader set of an individual’s PHI with another covered entity for the purpose of their disease management and chronic-care coordination.

AARP is concerned, however, that the proposed exception seems to emphasize relieving the data-hosting covered entity of the requirement to make a determination about the minimum information necessary when fulfilling a request from another covered entity. We urge you to put more onus on the requesting entity to specify what information it is asking for. A request for PHI, even for the purpose of care coordination and case management, should not be an open-ended, all-inclusive request to share data, but should be limited to the information necessary to meet the requestor’s purpose. In any event, we urge you to ensure that the individual is informed in a timely fashion that their PHI has been shared.

Clarifying the Scope of Covered Entities’ Abilities to Disclose PHI to Certain Third Parties

As stated above, AARP believes that it is reasonable for a covered entity to share a broader set of an individual’s PHI with another covered entity for the purpose of their disease management and chronic-care coordination. HHS proposes to expressly permit covered entities to disclose PHI to social services agencies, community-based organizations, home and community-based service providers, and similar third parties that provide or coordinate health-related services needed for individual care coordination and case management, even though these entities are not covered entities.

While AARP is generally supportive of this proposal, we believe sufficient guardrails and protections must be in place and urge you to limit disclosures to those services specifically identified in an individual’s care plan as agreed to by the provider, individual, and family. Furthermore, the individual must retain the ability to opt out of information sharing with third parties without impacting their care.
Encouraging Disclosures of PHI when Needed in Specific Circumstances

AARP strongly opposes the proposal to change the “exercise of professional judgement” standard to the “good faith belief” standard when covered entities are determining whether to share information with family members, caregivers, and friends who are trying to help an individual with a health-related emergency, substance use disorder, serious mental illness, and other instances where the individual is incapacitated or otherwise unable to express a privacy preference. HHS contends that the more flexible standard is needed to allow for determinations made by non-clinicians and to remove fear of penalties. This approach gives the benefit of the doubt to covered entities, when it should instead be exercising caution on behalf of the consumer.

We believe that abandoning the “professional judgement” standard is not in the best interest of consumers. First, it substitutes clinical guidance and best practices with personal interpretation and opinion. Second, if people have substance abuse disorders or serious mental illness, their HIPAA rights should not be overridden – and they could suffer even worse situations if they are. They could lose their jobs, lose their families, and lose their independence. Third, if someone is in a coma or if they are certified by a physician or psychologist to be unable to make their own decisions, then abridging their HIPAA rights could be accomplished more reasonably through established channels. Even if someone comes into a hospital and is actively on substances or they are suicidal and delusional, that condition could improve in a day or so, at which point the individual can decide to share or not share the details of their condition with family or friends. Overriding the person’s HIPAA protections should only be done when there is a clinically necessary reason.

Eliminating Notice of Privacy Practices Requirements

AARP strongly objects to HHS’s proposal to eliminate the requirement to obtain a written acknowledgement of receipt of the Notice of Privacy Practices (NPP). While far from perfect, the NPP is currently the best way to inform consumers about their rights to privacy and about how their protected health information might be shared. Removing this requirement would remove the principal way to hold providers accountable for actually informing consumers of their privacy rights. Instead, it opens the door to inadequate shortcuts, such as NPP wall posters or flashing the NPP on a check-in touch screen – both of which may be easily overlooked. Requiring the provider to obtain a signature highlights the privacy issue, signifies that the NPP is important and should not be overlooked, and gives the consumer the opportunity to digest the information. In the absence of a better system, HHS should maintain the written requirement which holds providers accountable for making consumers aware of their rights.
Conclusion

AARP appreciates the opportunity to comment on proposed changes to the Health Insurance Portability and Accountability Act Privacy Rule. We understand the challenges of balancing privacy and security with the desire to improve care through data sharing. As you update the Privacy Rule to respond to recent and future innovation, we urge that you ensure that people can retain control of the use of their own information and that individual and family-caregiver needs will be given the utmost priority. We look forward to working with you to ensure personal health data is used appropriately and responsibly in the delivery of care. If you have any questions feel free to contact me, or have your staff contact Andrew Scholnick of our Government Affairs team at ascholnick@aarp.org or 202-434-3770.

Sincerely,

David Certner
Legislative Counsel and Legislative Policy Director
Government Affairs