

February 12, 2019

Submitted Electronically

Roger Severino, Director
Office of Civil Rights
Department of Health and Human Services,
Attention: HHS-OCR-0945-AA00,
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue, SW, Washington, DC 20201

RE: Request for Information on Modifying HIPAA Rules to Improve Coordinate Care

Dear Director Severino,

Thank you for the opportunity to provide input on the Health Information Portability and Accountability Act (HIPAA) and its effect on care coordination. For patients, their caregivers and consumers across the country, HIPAA is a fundamental protection for people as they make their way through the health care landscape. The HIPAA Privacy and Security rules are necessary and core to protecting patient privacy.

The health technology landscape has evolved greatly in the last few years; we now have a much expanded universe of smartphone and mobile apps, remote monitoring devices, wearables and other consumer-facing apps that help to collect, send, manage and use one's health data. However, federal laws governing portability and privacy have not kept up.

As patient, caregiver and consumer advocates, we are supportive of efforts to improve care coordination and reform our health care delivery system. The lack of coordination and communication is a ubiquitous consumer complaint about the U.S. health care system, and is a key driver of poor quality and unaffordable care. We support appropriate and secure information sharing among team members to promote the best possible care outcomes, including with social service agencies and community-based support programs.

However, efforts to promote appropriate and secure information sharing should never come at the expense of patient confidentiality and trust.

As the end users of the health care system, there is a pressing need for consumers to shape health privacy and information sharing policy. Modifications to HIPAA must consider the potential impact on patient privacy and support patient involvement in discussions and decisions about their health information. We are also concerned there could 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.

We are eager to work with HHS/OCR to consider how best to promote patient privacy and care coordination. Our responses to specific questions are listed below and we welcome

additional conversation. If you have any questions about these recommendations, please contact Katie Martin at (202) 986-2600 or kmartin@nationalpartnership.org.

Sincerely,

AARP
Community Catalyst
Disability Rights Education and Defense Fund (DREDF)
Families USA
Justice in Aging
Legal Action Center
Medicare Rights Center
National Center for Transgender Equality
National Consumers League
National Health Law Program
National Institute for Reproductive Health (NIRH)
National Partnership for Women & Families
New Voices for Reproductive Justice
X4 Health

Responses to Questions posed in the Request for Information

a. Promoting Information Sharing for Treatment and Care Coordination

(2) How feasible is it for covered entities to provide PHI when requested by the individual pursuant to the right of access more rapidly than currently required under the rules?

As OCR assesses the feasibility of covered entities to accelerate responses to individual access requests, we encourage the Office to consider more than the provider perspective on this question. OCR should give equal consideration to what more timely access would mean to patients. Specifically, if covered entities provide protected health information (PHI) more rapidly than currently required, it would be much more feasible for a patient with a newly diagnosed illness to seek health care services and transfer the information she needs to get the right care and pursue the best possible health outcomes. We suggest that this feasibility be given equal weight.

(3) Should covered entities be required to provide copies of PHI maintained in an electronic record more rapidly than records maintained in other media when responding to an individual's request for access? (The Privacy Rule does not currently distinguish, for timeliness requirements, between providing PHI maintained in electronic media and PHI maintained in other media). If so, what timeframes would be appropriate?

Unequivocally, yes – patients and their authorized caregivers should be given faster access to their own health information. Individuals ideally need information within hours or several days, particularly for coordination and continuity of care. For many patients, the

days, weeks or even months it can take to get their health information is the difference between life and death: the ability to get a second opinion; to start treatment; to quality for an experimental drug; or to avoid an allergic reaction or other contraindication.

We strongly support the proposal to shorten the timeframe of the individual access requirement to less than 30 days, to motivate more rapid responses from covered entities and encourage them to seek technology solutions that better facilitate the provision of digital copies. Digital records in particular should be able to be produced more rapidly. We believe that the advancements in Electronic Health Record (EHR) standards and technology significantly reduce the time required to produce PHI electronically. 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.

(7) Should covered entities be required to disclose PHI when requested by another CE for treatment purposes? Should the requirement extend to disclosures made for payment and/or health care operations generally, or alternatively, only for specific payment or operations purposes?

Nearly 40 percent of individuals experience a gap in their health information when seeking care for a medical problem, such as having to tell a health care provider about her medical history or having to bring a test result to an appointment because records were not transferred from one doctor to another.¹ Often it is the patient and her family caregiver who must try to coordinate her care and the sharing of health information among her different providers. This places an additional burden on individuals who may lack the time, resources, capacity or desire to serve as an information conduit - while also trying to take care of themselves or a loved one. Indeed, we've heard from many patients and caregivers who express a desire for their doctors to "just talk to each other."

While we wholeheartedly embrace the idea that appropriate and secure information sharing between providers in the pursuit of patient-centered treatment should be the standard of care, we do not support a *requirement* for covered entities to disclose PHI when requested by another covered entity for treatment purposes. We oppose requiring disclosure for treatment purposes because we can imagine situations where disclosure could result in real harm to people. There are numerous reasons individuals may not want their health information shared with another covered entity. As HHS seeks to promote care coordination, we encourage the Department to safeguard and center patients' information sharing preferences. Preserving individuals' ability to control with whom their information is shared is paramount.

If we are truly putting patients at the center of their care, they should be involved in discussions about their treatment and related decisions regarding information sharing. Similarly, patients should have enhanced abilities to access their health information so that those who wish to do so are easily able to share/direct that information. We must make progress in technical capabilities around data segmentation to allow individuals to flag certain parts of their record as not to be shared without explicit permission.

While we oppose the proposal that covered entities be required to disclose PHI when requested by another CE for treatment purposes, deliberate efforts to restrict information sharing for competitive or financial reasons (“information blocking”) should not be tolerated.

(12) What timeliness requirement should be imposed on covered entities to disclose PHI that another covered entity requests for TPO purposes, or a non-covered health care provider requests for treatment or payment purposes?

From the consumer perspective, PHI should be shared as quickly as is practicable, assuming patient authorization as currently required. It is hard to imagine in a modern era any reason for significant delays, particularly for PHI that is created or held electronically in a standardized format. We encourage OCR to consider the shortest timeframe possible.

For many patients, the days, weeks or even months it can take to access or share their health information is the difference between life and death: the ability to get a second opinion, to qualify for an experimental drug or to avoid an allergic reaction or other contraindication. Every hour that is wasted exacts a toll on patients’ care and health outcomes. Requests to share information shouldn’t be taken lightly, or perceived as an administrative burden; appropriate and secure information should be treated as part of a broader mission to help people get better and stay healthy.

(13) Should individuals have a right to prevent certain disclosures of PHI that otherwise would be required for disclosure? For example, should an individual be able to restrict or “opt out” of certain types of required disclosures, such as for health care operations? Should any conditions apply to limit an individual’s ability to opt out of required disclosures? For example, should a requirement to disclose PHI for treatment purposes override an individual’s request to restrict disclosures to which a covered entity previously agreed?

Preserving individuals’ ability to control with whom their information is shared is paramount. We strongly object to overriding an individual’s request to restrict disclosures of their health information in any circumstance. We reiterate our objection to requiring disclosure for treatment purposes.

(16) What considerations should OCR take into account to ensure that a potential Privacy Rule requirement to disclose PHI is consistent with rulemaking by the Office of the National Coordinator for Health Information Technology (ONC) to prohibit “information blocking,” as defined by the 21st Century Cures Act?

While we oppose the proposal that covered entities be required to disclose PHI when requested by another CE for treatment purposes, deliberate efforts to restrict information sharing for competitive or financial reasons (“information blocking”) should not be tolerated.

Question 18 & 19: *Should OCR modify the Privacy Rule to clarify the scope of covered entities' ability to disclose PHI to social services agencies and community-based support programs where necessary to facilitate treatment and coordination of care with the provision of other services to the individual? Should OCR expressly permit disclosures of PHI to multi-disciplinary/multi-agency teams tasked with ensuring that individuals in need in a particular jurisdiction can access the full spectrum of available health and social services?*

Health care providers are increasingly recognizing that they cannot meet their patients' medical needs without also addressing their complex social and behavioral needs. For instance, some patients lack adequate transportation to their appointments or are forced to make difficult decisions between paying medical bills or other necessities like food and rent. Many health care providers are tackling these issues by partnering with social service providers to improve access to food, housing, transportation, education, job training and more. However, because of misconceptions and misinterpretations of the Privacy Rule, many others are not.

We believe providing holistic care and addressing adverse social determinants of health require health care and social service providers to share information, but we strongly believe this should not come at the expense of patient privacy. Fortunately, HIPAA already allows the exchange of patient information while also ensuring that this information remains protected and private.

The recently-released OCR guidance intended to clarify how health care providers can disclose PHI to organizations providing social services was a helpful first step. For example, OCR clarified that, "health care providers who believe that disclosures to certain social service entities are a necessary component of, or may help further, the individual's health or mental health care may disclose the minimum necessary PHI to such entities." However, perceived barriers and inconsistent interpretations by health care providers continue. Overcoming these perceived barriers is critical to increasing the willingness of partners to share data and provide more holistic, patient-centered care.

We do not believe it is necessary to modify the Privacy Rule or add express regulatory permission for covered entities to disclose PHI to social service agencies or community-based support programs because this is already permitted. However, we strongly encourage the following recommendations:

1. Provide additional clarifying, sub-regulatory guidance and Frequently Asked Questions to respond to the uncertainty that exists among covered entities about what information sharing is and what is not permitted.
2. Facilitate greater and improved education to health care providers and to patients and their caregivers regarding the provisions of HIPAA that permit uses and disclosures of PHI. Educational materials and training should be translated for real-life application. Information should be provided in ways that are accessible and understandable by all, including in multiple languages and for users with disabilities. OCR should have a strong infrastructure in place that is easily accessible to address questions and concerns from patients and families. Outreach and education should also include a focus on how state and other federal laws

interact with HIPAA, including situations where the Privacy Rule defers to state and other federal laws that include even stronger privacy protections.

3. Release educational materials tailored for social service providers, as it is also important for non-covered entities to understand the basic tenets of HIPAA in order to be effective partners and encourage a two-way exchange of data sharing.
4. Disseminate best practices to give both covered and non-covered entities examples of how others are successfully sharing information in compliance with HIPAA. For example, provide best practices on how to obtain patients' authorization for release of information or how to implement data-sharing agreements between covered and non-covered entities (such as a memorandum of understanding) as a feasible way to share information and protect privacy, while adhering to applicable regulations.

(21) Are there provisions of the HIPAA Rules that work well, generally or in specific circumstances, to facilitate care coordination and/or case management? If so, please provide information about how such provisions facilitate care coordination and/or case management. In addition, could the aspects of these provisions that facilitate such activities be applied to provisions that are not working as well?

HIPAA is a fundamental protection for people as they make their way through the health care landscape, and the HIPAA privacy and security rules are necessary and core to protecting patient privacy and maintaining confidentiality. In general, we believe the HIPAA rules strike an appropriate balance of keeping most health information private and secure, while also allowing for information to be shared with those who need it to provide the best possible patient care.

From our perspective, the bigger problem has, from HIPAA's inception, been the disregard for or misunderstanding of the law. The promise of HIPAA is thwarted by poor education/training and myopic implementation. Again, we believe that guidance and education related to the obligations of covered entities to share information with individuals and their authorized family caregivers, as well as the ability to share PHI with other providers, would help further advance care coordination, care management and consumer engagement.

b. Promoting Parental and Caregiver Involvement and Addressing the Opioid Crisis and Serious Mental Illness

We fully support care coordination, team-based care and caregiver involvement, based on the informed consent of the patient. As noted below, family caregivers are an important part of the health care system, and often provide important help and support to individuals. There are, however, important limits and safeguards in the Privacy Rule that delicately balance the need for the involvement of friends and family, while also protecting patients' desire for privacy and confidentiality, particularly around issues of substance use disorders, mental health and other sensitive health care issues.

Forty million family caregivers provide an estimated \$470 billion annually in unpaid care to their loved ones.² Indeed, research has found that without this family-provided help, “the economic cost to the U.S. health and long-term services and supports (LTSS) systems would skyrocket.”³ Family caregivers spend on average 24 hours a week caring for their loved ones; almost one-third of family caregivers provide an average of 62 hours of care a week.⁴

Family caregivers (broadly defined to include the patient’s chosen family) are often involved in assisting their loved ones, whether it is to help with daily activities such as eating, bathing, dressing and transportation; medical/nursing tasks such as managing multiple, complex medications or providing wound care; arranging and coordinating care among multiple providers and across multiple settings including acute care, specialty care, post-acute care, or long-term services and supports; providing emotional support; or paying out-of-pocket for services. Almost half of family caregivers perform medical/nursing tasks for individuals with multiple chronic physical and cognitive conditions.⁵ Family caregivers often serve as care coordinators, helping their loved ones navigate systems of care and different providers, especially – but not limited to – during care transitions. As OCR considers family caregivers and HIPAA, we encourage the Department to think about caregiving broadly and not just in specific situations.

Given the role that family caregivers often play in assisting, supporting, and advocating for their loved ones, it is important for family caregivers to have timely and appropriate access to information they need to assist them in making informed decisions and supporting their loved ones. For instance, coordination would be greatly facilitated if electronic health records included a field for the identification of family caregivers – especially since 40 states have enacted the Caregiver, Advise, Record, Enable (CARE) Act, which requires recording the name of the family caregiver when a loved one is admitted to a hospital. Yet we are concerned that HIPAA may be used as a reason for health care providers to withhold information or protected health information from family caregivers, when, in fact, HIPAA may already allow disclosure or sharing of information.

We urge OCR to further educate and clarify that HIPAA allows health care providers to share or discuss an individual’s health information with their family, friends or others involved in their care or payment for care, as long as the individual does not object. It is also important to clarify that providers may tell the individual that they plan to discuss the information and give the individual an opportunity to object, or may decide, using their professional judgement, that the individual does not object.⁶ We also know that an individual can consent to sharing their health information with family, friends or others.

We believe that additional education and outreach efforts to health care providers would help remove HIPAA as a *perceived* barrier to appropriate sharing of health information with family caregivers. The clarity resulting from additional education and outreach could help improve care coordination and case management involving family caregivers and the provision of care.

We also understand that patients’ relationships with family members and caregivers are extremely complex and varied. Indeed, the interests of the patient and caregiver may not always be aligned or in the best interest of the patient. The patient’s right to confidentiality is paramount, for example, in situations of current or potential elder abuse, intimate partner violence, or when patients (including minors) are seeking sensitive health care

services. In cases where the patient has decision-making capacity, or has engaged in a supported decision-making process, we strongly support – and believe that HIPAA protects – patients’ privacy and confidentiality above caregiver or family involvement.

(20) Would increased public outreach and education on existing provisions of the HIPAA Privacy Rule that permit uses and disclosures of PHI for care coordination and/or case management, without regulatory change, be sufficient to effectively facilitate these activities? If so, what form should such outreach and education take and to what audience(s) should it be directed?

Although HIPAA is often perceived as a barrier to information sharing and exchange, we believe the current regulations allow for appropriate information sharing. We believe that the regulatory framework of HIPAA is effective, but that properly resourced outreach and education can help alleviate the perceived burden while protecting patients’ informed consent, privacy and confidentiality. Outreach and education must be directed at multiple audiences, including providers, caregivers, and, importantly, patients themselves. Outreach and education should also include a focus on the how state and other federal laws interact with HIPAA, including situations where the Privacy Rule defers to state and other federal laws that include even stronger privacy protections.

(22) What changes can be made to the Privacy Rule to help address the opioid epidemic? What risks are associated with these changes? For example, is there concern that encouraging more sharing of PHI in these circumstances may discourage individuals from seeking needed health care services? Also is there concern that encouraging more sharing of PHI may interfere with individuals' ability to direct and manage their own care? How should OCR balance the risk and the benefit?

Privacy and confidentiality are the touchstones of effective management and treatment for substance use disorders. Treatment for substance use disorder remains significantly different from many other areas of medical treatment because of the legal ramifications associated with disclosure of substance use disorders including loss of employment, loss of housing, loss of child custody, loss of benefits, discrimination by medical professionals and arrest, prosecution and incarceration.⁷

We believe the patient should be at the center of their care, including directing and managing their own care and treatment. At the patient’s discretion, caregivers should be involved and incorporated into treatment planning for substance use disorders. We strongly believe that patients may be reluctant to share relevant information about substance use with providers or seek treatment if they are not assured of confidentiality.

OCR should consider better engagement and education to clarify to patients, providers and caregivers how information can currently be shared and accessed to allow for better care coordination and caregiver involvement for patients with substance use disorders.

(23) How can OCR amend the HIPAA Rules to address serious mental illness? For example, are there changes that would facilitate treatment and care coordination for individuals with SMI, or ensure that family members and other caregivers can be involved in an individual's care? What are the perceived barriers to facilitating this treatment and care coordination? Would encouraging more sharing in the context of SMI create concerns similar to any

concerns raised in relation to the previous question on the opioid epidemic? If so, how could such concerns be mitigated?

We fully support care coordination, team-based care, and caregiver involvement, based on the informed consent of the patient. Research shows that at least 8.4 million Americans provide care to an adult with an emotional or mental health issue and that these caregivers face complex, high-burden care situations, resulting in higher caregiver stress.⁸

As OCR has already stated in guidance, the Privacy Rule allows for routine communication between health care providers and family caregivers.⁹ When a patient is present, health care providers may communicate with a patient's family members, friends, or other individuals involved in their care (or payment for care), so long as the patient does not object (See 45 CFR 164.510(b)).¹⁰

OCR should consider better engagement and education to clarify for patients, providers, and caregivers how information can be currently be shared and accessed to allow for better care coordination and caregiver involvement for patients with serious mental illness.

(25) Could changes to the Privacy Rule help ensure that parents are able to obtain the treatment information of their minor children? If the Privacy Rule is modified, what limitations on parental access should apply to respect any privacy interests of the minor child?

We oppose changing the Privacy Rule to make it easier for parents to obtain the treatment information of their minor children. Parents already have considerable access to the treatment records for their children, as parents or guardians are generally considered the minor's personal representative and can exercise the minor's rights with respect to protected health information.¹¹

OCR should maintain the current limitations on parental access in the following circumstances: 1) when state or other law does not require the consent of a parent or other person before a minor can obtain a particular health care service; 2) when someone other than the parent is authorized by law to consent to a particular health services for a minor; 3) when a parent agrees to a confidential relationship between the minor and a health care provider; and 4) when a provider believes that a minor is subject to abuse, neglect or endangerment.¹²

In addition, we strongly support OCR's overarching deference to other federal and state laws for safeguarding minors' privacy and confidentiality. If OCR were to change the policy of deferring to state law, we believe that would create greater confusion about how and where the HIPAA Privacy Rule applies.

According to a recent article in the American Medical Association Journal of Ethics, patients who have the greatest fear of breaches of confidentiality include "those seeking sensitive services such as reproductive and sexual health, mental health services, substance use treatment; adolescents; those affected by domestic or intimate partner violence; and those covered as dependents on a family member's health insurance policy."¹³

The Privacy Rule currently recognizes that some minors would not seek needed health care services if they could not receive it confidentially. Approximately, a quarter of high school students report having forgone needed health care; many of them cite not wanting to tell their parents as a specific reason for avoiding care.¹⁴ The impact of privacy concerns is even higher when adolescents are seeking health care services such as treatment for sexually transmitted infections, pregnancy prevention, substance use, and mental health.¹⁵

We strongly recommend that OCR maintain the current balance in generally allowing parents' access to minors' health information while also protecting minors' right to privacy in specific circumstances.

(25) (b) Should any changes be made to specifically allow parents or spouses greater access to the treatment information of their children or spouses who have reached the age of majority? If the Privacy Rule is changed to encourage parental and spousal involvement, what limitations should apply to respect the privacy interests of the individual receiving treatment?

We do not believe that changes that would allow parents to have increased access to the treatment information of their adult children are appropriate. The Privacy Rule already allows such access with permission of the patient or if the patient does not object. Likewise, we do not believe that OCR should make changes to the Privacy Rule to make it easier for spouses to obtain the treatment information of their partner. The limitations already in place are an important protection in the case of a spouse seeking sensitive health services and/or in cases of intimate partner violence. Maintaining confidentiality for survivors of intimate partner violence is paramount to preserving the safety, privacy, and trust of those seeking services.¹⁶

d. Notice of Privacy Practices

(53) (b) OCR has received anecdotal evidence that individuals are not fully aware of their HIPAA rights. What are some ways that individuals can be better informed about their HIPAA rights and how to exercise those rights? For instance, should OCR create a safe harbor for covered entities that use the model NPPs by deeming entities that use model NPPs compliant with the NPP content requirements?

We agree that awareness of individuals' rights under HIPAA is unacceptably low. Unfortunately, few individuals or providers understand the rights patients have to access and direct their health information - especially electronically. There is also extremely low awareness of permissible forms of information sharing – with other providers as well as with non-covered entities – under the law. More education is always helpful – but we stress the need for substantial and meaningful education among the health care provider community with complementary education efforts focused on patients and families.

From our perspective, the bigger problem has, from HIPAA's inception, been the disregard for or misunderstanding of the law. HHS has done a laudable job communicating the importance of keeping patients' health information private and secure – which is critical to maintaining patient trust. However, the nuances of the law's provisions regarding

information sharing have been lost; the complexities are unjustly boiled down to “HIPAA means no [sharing].”

We are concerned that poor training and myopic implementation of the HIPAA Privacy and Security rules are contributing to the lack of understanding of how the law currently allows PHI to be shared for the purposes of care coordination. We agree that more education and training is needed, but the current approach is not sufficient. We encourage the Department to explore substantive, targeted, meaningful approaches to education and training that emphasize what information sharing is currently permissible under HIPAA. OCR should examine best practices for effectively tailoring educational efforts to trainees’ unique needs (e.g., different issues, information needs for a doctor, administrative staff, IT staff, etc.).

We also encourage OCR to consider how the Office can better serve as a “trusted source” of information about the HIPAA privacy and security rules, specifically with regard to permissible information sharing and care coordination efforts. We are familiar with the impressive materials the Office has produced in recent years to address the awareness gap (e.g., [guidance](#), FAQs, fact sheets, and educational videos on important topics such as [Your Health Information, Your Rights](#); [The Right to Access and Correct Your Health Information](#); and [Your New Rights Under HIPAA](#)). Unfortunately, these resources have not reached those who need them the most – neither the health care providers and administrators working on the front lines to respond to information requests, nor the patients and families trying to navigate the complexities of the health care system.

In addition to developing new approaches, we encourage OCR to consider how to increase dissemination of these and other educational resources. For example, leveraging social media by creating an OCR/HIPAA Twitter handle, dedicated to disseminating departmental information, guidance, and other resources related to HIPAA privacy and security. Several federal agencies have harnessed the power of social media to effectively share critical information with large numbers of stakeholders (e.g., ONC and CDC). People need to learn how information can be appropriately and securely shared under the current HIPAA rules, directly from the regulators and enforcers (OCR itself).

The Department must also demonstrate the seriousness with which it takes HIPAA. HHS could make real progress by investing as much time, energy, resources, into promoting, enforcing and educating providers on the privacy rule – particularly the individual right of access – as it does considering regulatory changes.

This includes careful monitoring and public transparency regarding HIPAA privacy and security enforcement efforts. We appreciate the data OCR already provides about its enforcement activities (e.g., enforcement highlights, case examples, resolution agreements) and encourage the Department to provide more detailed information. For example, providing raw numbers or percentages regarding the number and types of enforcement violations per year. (“Access” is listed as the [top enforcement issue in investigated cases for 2016](#), but it is unclear what percentage of overall cases these Access issues represent).

We encourage OCR to consider how it may be able to leverage its oversight and enforcement authority (including issuing civil monetary penalties), to facilitate individuals' ability to access and direct their health information.

e. Additional Ways To Remove Regulatory Obstacles and Reduce Regulatory Burdens To Facilitate Care Coordination and Promote Value-Base Health Care Transformation

(54) In addition to the specific topics identified above, OCR welcomes additional recommendations for how the Department could amend the HIPAA Rules to further reduce burden and promote coordinated care.

We appreciate the opportunity to provide additional input on how to promote value-based health care transformation – particularly from the perspective of consumers, patients and family caregivers.

The health technology landscape has evolved greatly in the last few years; we now have a much expanded universe of smartphone and mobile apps, remote monitoring devices, wearables and other consumer-facing apps that help to collect, send, manage and use one's health data. Gaps in the current health data regulatory patchwork mean that much of the data currently being generated and used in health care (e.g., patient-generated data, personally identifiable data, "big data") do not have robust privacy and security protections. Indeed, the same data might or might not be subject to HIPAA's privacy and security protections depending upon whether it was created or stored by a covered entity (such as a doctor or payer) or an individual patient (e.g., clinical data downloaded to a mobile app). As new technologies continue to develop and proliferate, they will produce new data without a clear framework governing who controls it, who has access to it, who is responsible for protecting it and whether it will be able to interact with the rest of the health care system.

We know that the same health data can be used for good (e.g. identifying and reducing health disparities) or harm (e.g. community profiling and redlining). A growing number of tech companies, including data brokers like LexisNexis, are compiling and selling data about patients' criminal records, voter registration, retail history, grocery purchases and more – without patient knowledge. This data can be legally purchased by health care providers looking to drive better medical decision making (e.g., identify patients at risk of hospital readmission). These and other practices of acquiring and using patient data to make decisions about health care have serious implications for patient privacy and discrimination in access to care, insurance or employment – further exacerbating disparities in health care treatment and outcomes.

There is an urgent need for a more expansive conversation about how to responsibly and ethically collect, use and share data for health. We are eager to work with HHS/OCR to consider how best to promote patient privacy and care coordination and we welcome additional conversation about the best ways to solicit the consumer perspective in emerging conversations about health privacy and information sharing.

¹ Patel, V., Barker, W., & Siminerio, E. (2014, September). *Individuals' Access and Use of their Online Medical Record Nationwide*. (ONC Data Brief No. 20). Retrieved 25 January 2019, from https://www.healthit.gov/sites/default/files/consumeraccessdatabrief_9_10_14.pdf

² Reinhard, S., Feinberg, L.F., Choula, R & Houser, A. (2015, July 15). *Valuing the Invaluable: 2015 Update, Undeniable Progress, but Big Gaps Remain*. AARP Public Policy Institute. Retrieved 18 January 2019, from https://www.aarp.org/ppi/info-2015/valuing-the-invaluable-2015-update.html?cmp=RDRCT-VALUN_JUN23_015

³ *Ibid.*

⁴ National Alliance for Caregiving. (2015, June 4). *Caregiving in the U.S. 2015: Executive Summary*. AARP Public Policy Institute. Retrieved 18 January 2019, from http://www.aarp.org/ppi/info-2015/caregiving-in-the-united-states-2015/?cmp=CRGVNUSA_MAY21_015

⁵ Reinhard, S.C., Levine, C., & Samis, S. (2012, October). *Home Alone: Family Caregivers Providing Complex Chronic Care*. AARP Public Policy Institute and United Hospital Fund. Retrieved 20 January 2019, from http://www.aarp.org/content/dam/aarp/research/public_policy_institute/health/home-alone-family-caregivers-providing-complex-chronic-care-rev-AARP-ppi-health.pdf

⁶ Office for Civil Rights. *When health care providers may communicate about you with your family, friends, or others involved in your care*. Retrieved 19 January 2019, from https://www.hhs.gov/sites/default/files/ocr/privacy/hipaa/understanding/consumers/consumer_ffg.pdf; Office for Civil Rights. (2017, June 16). *Family Members and Friends*. Retrieved 21 January 2019, from <https://www.hhs.gov/hipaa/for-individuals/family-members-friends/index.html>; Office for Civil Rights (2013, July 26). *If I do not object, can my health care provider share or discuss my health information with my family, friends, or others involved in my care or payment for my care?*. Retrieved 31 January 2019, from <https://www.hhs.gov/hipaa/for-professionals/fag/488/does-hipaa-permit-a-doctor-to-discuss-a-patients-health-status-with-the-patients-family-and-friends/index.html>, <https://www.hhs.gov/hipaa/for-individuals/fag/523/can-my-health-care-provider-share-or-discuss-my-health-information-with-my-family/index.html>; Office for Civil Rights (2013, July 26). *Does the HIPAA Privacy Rule permit a doctor to discuss a patient's health status, treatment, or payment arrangements with the patient's family and friends?*. Retrieved 31 January 2019, from <https://www.hhs.gov/hipaa/for-professionals/fag/488/does-hipaa-permit-a-doctor-to-discuss-a-patients-health-status-with-the-patients-family-and-friends/index.html>. We urge HHS OCR to further educate and clarify this information for health care providers.

⁷ Lopez, K., Reid, D. (2017, April 13). *Discrimination Against Patients with Substance Use Disorders Remains Prevalent and Harmful: The Case for 42 CFR Part 2*. Health Affairs Blog. Retrieved 25 January 2019, from <https://www.healthaffairs.org/doi/10.1377/hblog20170413.059618/full/>

⁸ National Alliance for Caregiving (2016, February). *On Pins and Needles: Caregivers of Adults with Mental Illness*. Retrieved 25 January 2019, from https://www.caregiving.org/wp-content/uploads/2016/02/NAC_Mental_Illness_Study_2016_FINAL_WEB.pdf

⁹ Office for Civil Rights. *HIPAA Privacy Rule and Sharing Information Related to Mental Health*. Retrieved 25 January 2019, from <https://www.hhs.gov/sites/default/files/hipaa-privacy-rule-and-sharing-info-related-to-mental-health.pdf>

¹⁰ *Ibid.*

¹¹ Office for Civil Rights. (2013, September 19). *Personal Representatives*. Retrieved 25 January 2019, from <https://www.hhs.gov/hipaa/for-professionals/privacy/guidance/personal-representatives/index.html>

¹² *Ibid.*

¹³ English, A., Lewis, J. (2016, March). Privacy Protection in Billing and Health Insurance. *AMA Journal of Ethics*. 18(3), 279-289. Retrieved 25 January 2019, from <https://journalofethics.ama-assn.org/article/privacy-protection-billing-and-health-insurance-communications/2016-03>

¹⁴ English, A., Ford, C.A., (2004, March/April). The HIPAA Privacy Rule and Adolescents: Legal Questions and Clinical Challenges. *Perspectives on Sexual and Reproductive Health*, 36(2), 80-86. Retrieved 29 January 2019, from <https://www.guttmacher.org/journals/psrh/2004/hipaa-privacy-rule-and-adolescents-legal-questions-and-clinical-challenges>

¹⁵ *Ibid.*

¹⁶ National Network to End Domestic Violence. *Confidentiality Toolkit*. Retrieved 29 January 2019, from [https://www.techsafety.org/confidentiality/ /](https://www.techsafety.org/confidentiality/)