February 12, 2019

Mr. Roger Severino
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: Document Number HHS-OCR-0945-AA00: Request for Information on Modifying HIPAA Rules to Improve Coordinated Care

Dear Director Severino:

Thank you for soliciting feedback on how the Health Insurance Portability and Accountability Act (HIPAA) privacy and security regulations could facilitate more efficient and coordinated care for patients. As part of this request for information (RFI), the Office for Civil Rights (OCR) seeks input on modifications to HIPAA regulations that could promote information sharing among health care providers and patients. To meet these goals, OCR should work with the Office of the National Coordinator for Health Information Technology (ONC), the federal agency that oversees electronic health records (EHRs), to implement effective solutions to two key barriers that inhibit the exchange of information: ineffective patient matching, and the insufficient extraction and use of data from patients' records.

The Pew Charitable Trusts is a non-profit research and policy organization with several initiatives focused on improving the quality and safety of patient care, facilitating the development of new medical products and reducing costs. Pew's health information technology initiative focuses on advancing the interoperable exchange of health data and improving the safe use of EHRs.

OCR released the RFI to obtain input on how the agency could modify HIPAA regulations—particularly the Privacy Rule, which governs patients' rights to access their health data and other aspects of data sharing—to promote more coordinated care for patients while preserving privacy protections. The Privacy Rule enables patients to obtain and direct the exchange of their medical information among the health care providers where they seek care. However, that does not always effectively occur, as patients may have to wait weeks to obtain their records or only be able to obtain their information in less-useful formats—such as large stacks of documents or via CDs.[1]

In considering modifying HIPAA rules, OCR requests information on barriers to information sharing and patients' ability to access their health data, including factors that affect the timely exchange of medical records. OCR indicates that delays in the transfer of records between health care organizations results in patients and clinicians not having the information they need for treatment.

Several barriers hamper effective information sharing among health care providers and the ability of patient to access their records. Pew focuses on two of those challenges: ineffective patient matching and insufficient use of electronic tools to facilitate the exchange of data. First, for organizations to exchange data, such as to transfer a summary of care to another facility, they must correctly associate records for the same individual, known as patient matching. Second, patients encounter barriers in securing access to their records—when requested by them or when they want their data sent to another entity involved in their care. Application programing interfaces (APIs)—which are software tools that enable different technologies to easily transfer data—can help address this challenge by facilitating communication between systems. OCR should work with ONC to support enhancements to patient matching through enhanced standards for demographic data and effective adoption of APIs to facilitate enhanced access to and communication of health data.

Enhanced patient matching can improve record transfers
In this RFI, OCR requests information on barriers faced by health care providers when seeking records from other organizations, and challenges encountered by patients—particularly regarding timeliness—when accessing their information. For example, OCR references that health care facilities may not respond to other organizations' requests for records.

Hospitals may not respond to a record request or patients might not get their data for many reasons—such as the perception that HIPAA does not allow the sharing of certain data or because certain policies restrict the transfer of sensitive information (e.g. substance use histories). In addition, challenges with patient identification and matching also hinder health care organizations' ability to respond to other providers' requests for patient information. For example, health care providers may not know they have records for the patient whose information is requested—either by another hospital or directly by the individual. A new American Hospital Association report indicates that 37 percent of health care providers surveyed cite patient identification and matching as a common barrier to the exchange of information.[2]

Failures to identify the right records that facilities have on file occur, in part, because organizations can use different data and formatting for the information. The lack of consistent demographic data and the standards used for the information can affect the ability of automated algorithms to match records. Health executives interviewed by the Massachusetts eHealth Collaborative (MAeHC) in conjunction with Pew indicated that medical facilities often rely solely on these automated algorithms, and therefore may not respond to record sharing requests when those processes fail.[3] In some situations, health care facilities also use personnel to help match records. Those manual processes can add time and costs to match records and send the right files to patients or other providers. Lack of consistent standards to facilitate improved automated algorithmic matching also delays the ability of health care facilities to respond to record requests because manual adjudication is needed.

To address variability in the demographic information used by algorithms, many organizations have recommended the standardization of data—both by using and respresenting elements in the same way. Recently, a report released last month by the Government Accountability Office—in response to a provision in the 21st Century Cures (Cures) Act, passed in 2016—highlighted demographic data standardization as a way to improve patient matching.[4]

Pew-funded research conducted by Indiana University's Regenstrief Institute tested whether demographic data standardizaion improves match rates. The research indicated that standardizing certain demographic data, particularly address, can meaningfully improve match rates. Other research has shown that some demographic information—such as email address—are increasingly recorded in EHRs but typically not used for matching. For example, one study found that in 2014 more than half of health records contained patients' email addresses.[5]

To enable health care facilities to more quickly and comprehensively respond to record requests, OCR should work with ONC to standardize the data used for matching. Specifically, OCR should encourage ONC to advance standards for some demographic data (e.g. use of the U.S. Postal Service standard for address) and the availability of additional data for matching, such as email address. ONC could make these changes, for example, via the agency's proposed U.S. Core Data for Interoperability (USCDI)—a group of data elements that builds on the Common Clinical Data Set (CCDS), which is key information, such as medication lists, that should be exchanged. Through collaboration with ONC, OCR can advance its goal of more timely responses to record requests by health care providers to promote coordinated care.

Use of APIs can further accelerate patient, provider access to data
In addition to matching, the inability to effectively extract data from EHRs can also hinder patient and provider access to information. These challenges can occur, for example, when patients want their data downloaded onto their smartphone or request that health care providers treating them share medical records—including sensitive data. These information-sharing challenges underpin various questions in the RFI regarding the timeliness of patients getting their information, the efficiency of electronic data exchange among health care providers, and the availability of information.

Health record data may not be effectively made available to patients or clinicians based on how the information is accessed and formatted. ONC regulations currently require that for EHRs to meet the most recent criteria established by the agency, systems must be able to grant patients access to some data via APIs. Those regulations require that EHRs only make the CCDS available via APIs for patient access to their information. While the CCDS includes important data—such as problem lists—it also lacks key information, such as clinical notes and radiology report data—that patients may not be able to access via these APIs. In addition, ONC and the Centers for Medicare & Medicaid Services encourage the exchange of the CCDS as part of transitions of care—such as when a patient is discharged from the hospital. In those cases, health care providers reviewing records from other facilities and patients may lack key data outside the CCDS to inform medical decisions.

To further enhance the ability of patients and clinicians to effectively obtain the information they want and need to improve and better coordinate care, OCR should work with ONC to advance the effective use of APIs. These tools can help ease the extraction of data from EHRs so that the information can be easily made available and used by patients and clinicians.

In the Cures Act, Congress prioritized the use of APIs by requiring ONC to establish requirements for EHRs to make "all data elements" available via these tools "without special effort". Once

established, implemented, and used, the new "open" APIs—which would still have security and privacy protections in place—could allow patients to download many aspects of their medical records in an effective and timely way. These open APIs could also ensure that when patients want their data exchanged among or used by health care providers, fewer barriers restrict the exchange of information.

To facilitate enhanced data exchange, OCR should work with ONC on its implementation of these APIs so that patients can get and direct the sharing of their health records in a prompt and comprehensive manner, including for sensitive information that they want exchanged. Specifically, OCR should encourage ONC to make more data than the CCDS available via APIs—including enabling patients to receive clinical notes and sensitive data. OCR should also urge ONC to facilitate the use of standards—such as Fast Healthcare Interoperability Resources protocols and clinical data terminologies—that ease the exchange of information. Coordination with ONC can ensure that ONC's regulations on APIs help meet OCR's goals of better data exchange with patients and among clinicians to enhance the coordination of care.

Conclusion
Via this RFI, OCR seeks to enhance care coordination by promoting individuals' access to their data, and encourage more effective and timely data sharing among clinicians treating the same patient. To achieve those goals, the agency should collaborate with ONC on ways to enhance patient matching through more robust demographic data standards and enable APIs to effectively extract data from records.

Thank you for the opportunity to provide comments on ways that OCR can facilitate the improved exchange of health data. Should you have any questions or if we can be of assistance, please contact me at 202-540-6333 or bmoscovitch@pewtrusts.org.

Ben Moscovitch
Project Director, Health Information Technology
The Pew Charitable Trust

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[1]CommunicateHealth, Inc., "Improving the Health Records Request Process for Patients: Insights from User Experience Research" (2017), https://www.healthit.gov/sites/default/files/onc_records-request-research-report_2017-06-01.pdf and Lana Moriarty, "Understanding the Patient Experience to Improve Patient Access to Medical Records," *Health IT Buzz* (blog), July 11, 2017, https://www.healthit.gov/buzz-blog/consumer/understanding-patient-experience-improve-patient-access-medical-records; GetMyHealthData, "Patient Stories," https://getmyhealthdata.org/stories/.
[2] American Hospital Association, "Sharing Data, Saving Lives: The Hospital Agenda for Interoperability," Jan 2019, https://www.aha.org/guidesreports/2019-01-22-new-report-national-hospital-associations-outline-agenda-interoperability
[3] The Pew Charitable Trusts, "Enhanced Patient Matching Is Critical to Achieving Full Promise of Digital Health Records: Accurately linking individuals with their records essential to improving care," Oct. 2, 2018, https://www.pewtrusts.org/en/research-and-analysis/reports/2018/10/02/enhanced-patient-matching-critical-to-achieving-full-promise-of-digital-health-records
[4] Government Accountability Office, "Health Information Technology: Approaches and Challenges to Electronically Matching Patients' Records across Providers" (2019), https://www.gao.gov/products/GAO-19-197
[5] Adam Culbertson et al., "The Building Blocks of Interoperability: A Multisite Analysis of Patient Demographic Attributes Available for Matching," Applied Clinical Informatics 8, no. 2 (2017): 322-336, https://doi.org/10.4338/ACI-2016-11-RA-0196.