

National Indian Health Board



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February 12, 2019

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

RE: Comments on Request for Information (RFI)—Modifying HIPAA Rules to Improved Coordinated Care

Dear Director Severino:

On behalf of the National Indian Health Board (NIHB)¹ and the 573 federally recognized Tribal Nations that we serve, I write to submit comments in response to the Office for Civil Rights Request for Information (RFI) entitled: *Modifying HIPAA Rules to Improve Care Coordination*.

Background

The Indian health system—collectively, the Indian Health Service/Tribal Health Facilities/Urban Indian Health Programs (I/T/U) system, strives to provide safe, trusted, high quality health care to American Indians and Alaska Natives (AI/ANs) across the continuum of care. The Indian Health Service (IHS), an agency within the Department of Health and Human Services (HHS), operates

¹ Established in 1972, NIHB is an inter-Tribal organization that advocates on behalf of Tribal governments for the provision of quality health care to all American Indians and Alaska Natives (AI/ANs). The NIHB is governed by a Board of Directors consisting of a representative from each of the twelve Indian Health Service (IHS) Areas. Each Area Health Board elects a representative to sit on the NIHB Board of Directors. In areas where there is no Area Health Board, Tribal governments choose a representative who communicates policy information and concerns of the Tribes in that area with the NIHB. Whether Tribes operate their entire health care program through contracts or compacts with IHS under Public Law 93-68, the Indian Self-Determination and Education Assistance Act (ISDEAA), or continue to also rely on IHS for delivery of some, or even most, of their health care, the NIHB is their advocate.



as part of the I/T/U system and is responsible for providing health services to around 2.3 million AI/ANs in the United States. The goal of IHS is to ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to all AI/AN people. The foundation of IHS is to uphold the Federal Government obligation to promote healthy American Indian and Alaska Native people, communities, and cultures, and to honor and protect the inherent sovereign rights of tribes.

IHS operates twenty-eight acute-care hospitals² dispersed across a total of twelve service Areas and one-hundred seventy IHS and Tribally managed service units. Tribally operated health care services, which were created under Titles I and V of the Indian Self-Determination and Education Assistance Act (Public Law 93-638), provide Tribes the option to exercise self-determination by assuming control and management of health programs that were previously administered at the federal level through IHS. Currently, approximately sixty-percent of IHS appropriations are allocated and administered by Tribes through contracts and compacts. There are also a total of forty-one Urban Indian Organizations.³

As covered entities under the Health Insurance Portability and Accountability Act of 1996 (HIPAA), I/T/U facilities and programs will be directly affected by the proposed modifications to the HIPAA Privacy, Security, and Enforcement Rules, many of which are mandated by the Health Information Technology for Economic and Clinical Health Act (HITECH Act). Thus, providing an accurate portrait of Indian Country in terms of data and ensuring this data is safeguarded is essential.

AI/AN populations continue to be underreported and racially misclassified when it comes to health needs in Indian Country as a result of under sampling in both the state and national surveillance systems registries. Since many disease registries rely on mortality data to accurately assess health status and AI/ANs are often misclassified, this subset of the population is underrepresented.⁴ Studies have also shown that racial misclassification is greater outside IHS Purchased/Referred Care (PRC) Delivery Areas and continues to be an issue throughout Indian Country.⁵ As a result, federal agencies do not have access to the full picture of health disparities plaguing Indian Country. This means that AI/AN health needs fail to appear on the national agenda, leading to less funding overall for Tribal communities.

While the RFI proposes a number of possible modifications to the HIPAA Rules, NIHB's comments will focus on the following goals as outlined in the RFI: (1) promoting information sharing for treatment and care coordination; and (2) promoting parental and caregiver involvement

² Department of Health and Human Services. Office of Inspector General. Indian Health Service Hospitals: Longstanding Challenges Warrant Focused Attention to Support Quality Care. (October 2016), <https://oig.hhs.gov/oei/reports/oei-06-14-00011.pdf>.

³ Indian Health Service. IHS Profile. (July 2018), <https://www.ihs.gov/newsroom/factsheets/ihsprofile/>.

⁴ Northwest Tribal EpiCenter, Racial misclassification and disparities in mortality among American Indians/Alaska Natives and other races, <https://www.hcup-us.ahrq.gov/datainnovations/raceethnicitytoolkit/or26.pdf>.

⁵ See Jim, M. A., Arias, E., Seneca, D. S., Hoopes, M. J., Jim, C. C., Johnson, N. J., & Wiggins, C. L. (2014). Racial misclassification of American Indians and Alaska Natives by Indian Health Service Contract Health Service Delivery Area. *American journal of public health, 104 Suppl 3*, S295-302.

and addressing the opioid crisis and Serious Mental Illness. NIHB's recommendations are outlined in the subsequent sections.

Promoting Information Sharing for Treatment and Care Coordination

Indian Health System participate in many different efforts to coordinate care. As an example, the I/T/U system utilizes integrated care delivery models. Notably, the Improving Patient Care (IPC) model and the IHS Care Model serve as conduits to enhance the patient experience and corroborate these efforts with quality improvement (QI) initiatives.⁶ Reassurance of the safety and privacy of Protected Health Information (PHI) between patient and providers serves as a means to provide quality and reliable care. The Privacy Rule permits, but does not require, covered entities to use and disclose PHI for treatment, payment, health care operations (TPO) purposes.⁷

The RFI asks whether covered entities should be required to disclose PHI when requested by another covered entity for treatment purposes. Section 164.522(a) of the Privacy Rule requires that covered entities must permit individuals to request restrictions on the use or disclosure of an individual's PHI for purposes relating to treatment, payment, or health care operations, as well as certain disclosures to an individual's family members. For Tribal health care systems, permitting disclosure between covered entities for treatment purposes would enhance critical and timely care for some of the most vulnerable populations served (e.g. those with chronic diseases and serious mental illness) who all too often need care from multiple entities. Tribes have also acknowledged that these requests for treatment records would apply for treatment purposes only and not for payment or health care operations, in order to maximize the individual patient's privacy while simultaneously coordinating his or her care in a timely and efficient manner.

The Office for Civil Rights (OCR) asks whether exceptions or limitations should be implemented as a requirement for covered entities to disclose PHI to other health care providers (or other covered entities) upon request and whether these PHI disclosures be referred to a designated record set. Tribal health entities have stated that certain PHI should be limited within a designated record set. For example, psychotherapy notes, for substance use treatment and other forms of sensitive

⁶ Indian Health Service, Improving Patient Care (IPC), <https://www.ihs.gov/ipc/>.

⁷ "Treatment means the provision, coordination, or management of health care and related services by one or more health care providers, including the coordination or management of health care by a health care provider with a third party; consultation between health care providers relating to a patient; or the referral of a patient for health care from one health care provider to another." 45 CFR 164.501 (definition of "treatment"); also see 45 CFR 164.502(a)(1)(ii) and 164.506. The definition of "health care operations" includes, but is not limited to "any of the following activities of the covered entity to the extent that the activities are related to covered functions: (1) Conducting quality assessment and improvement activities, including outcomes evaluation and development of clinical guidelines, provided that the obtaining of generalizable knowledge is not the primary purpose of any studies resulting from such activities; patient safety activities (as defined in 42 CFR 3.20); population-based activities relating to improving health or reducing health care costs, protocol development, case management and care coordination, contacting of health care providers and patients with information about treatment alternatives; and related functions that do not include treatment . . .".

PHI, such as genetic information, should be excluded from disclosure requirements for covered entities unless the individual or legal representative consent to including these records.

The RFI also addresses disclosure deadlines among covered entities where one covered entity makes a request to another for TPO purposes. Currently, covered entities are allotted thirty-days to disclose requested PHI and this applies to requests made between covered providers and health plans. Tribes feel that provider-to-provider disclosures of PHI for treatment providers must be done as expediently as possible. The same is true for Electronic Health Record (EHR) PHI disclosure requests; Tribes have suggested that EHR related requests be sent to the requesting provider within 1-2 business days to prevent any costly and potentially harmful delays in treatment.

The OCR also seeks comments as to whether explicit affirmative authorization is required of the patient prior to a covered entity initiating a request for PHI on behalf of the patient, or whether the covered entity may substitute its own good faith, professional judgement to gather that information. In response to this inquiry Tribes request that, whenever possible, a covered health care provider should attempt to secure at least a verbal and/or written consent from the patient in order to share PHI with another covered health care provider. However, in the case of an emergency, a request can be based on the entity's professional judgement as to the best interest of the patient.

Next, the OCR requests information on how a general requirement for covered health care providers (or all covered entities) to share PHI when requested by another covered entity interacts with other laws, such as 42 Code of Federal Regulations (CFR) Part 2.⁸ Tribes have expressed it would be helpful to have guidance aligning 42 CFR with HIPPA standards. If this were to occur, sharing information regarding treatment services for co-occurring issues would simplify mechanisms for providing integrated services internally and externally. It would enable providers to identify areas of need and treatment if they were able to share information seamlessly through EHR with Primary Care Providers (PCP) and other service providers.

- Due to 42 CFR part 2 Tribes are not able to make referrals or share information specific to their clients unless they have a signed Release of Information (ROI). If Tribes were to abide by HIPPA only, then Tribes could share information more freely across Indian Health Care Providers and would be considered to be under the same healthcare institution and therefore not need the ROI.
- 42 CFR part 2 limits who is able to see notes (in fact, only clinicians working directly on addiction are able to see notes). This limits continuity of care across providers, as an individual's primary care provider, other mental health providers, pharmacists, etc., are not able to see information that would be beneficial (i.e. reports, key notes, medications) to continuity of care.

Within Indian Country, patients access a multitude of services through social service agencies as well as community-based support programs. It is therefore imperative to Tribal health care systems that ONC clarify the scope in which covered entities are able to disclose PHI to the

⁸ Confidentiality restrictions and safeguards. 42 C.F.R. §2.13 (2017).

aforementioned and other agencies and programs. Specifically, if the OCR were to permit disclosures of PHI to multi-disciplinary/multi-agency teams with the aim of providing a full spectrum of care and services, this would reduce the “silo” effect of having agencies and, sometimes, programs within the same agency, unable to communicate fully regarding care and services for an individual.

- This inability to share information results in agencies duplicating treatment efforts, which can be costly, and potentially harmful to the individual seeking care. For example, an individual may receive a mental health assessment after discussing a trauma. If not all mental health providers have access to this assessment, the individual may be asked, repeatedly, to discuss their trauma, effectively re-traumatizing the individual.
- External auxiliary services are essential to meeting individuals’ basic needs, which become important for treatment outcomes. For example, it is difficult to focus on mental health treatment if an individual does not know where their next meal will come from. Reducing the need for ROIs to coordinate treatment would expedite services delivered to individuals who are in the greatest need of care.

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

Across Indian Country, Tribal health providers frequently report difficulty navigating federal and state health information privacy laws and regulations. This creates inequality in instances where individuals with certain disorders, such as substance abuse, should have the same access to the benefits of seamless, coordinated care, as individuals without a substance abuse disorder.

Chronic and serious mental illness often requires wrap-around care involving many entities, both internal and external. The OCR requests that commenters provide information as to mechanisms that will ensure the best continued outcomes and timely care for vulnerable populations. Tribes believe that shortening the response time for an individual’s request for records from 30 days to 15 days with a one-time possible extension of 10 days is one way to contribute to better health and recovery outcomes and timely care. Additionally, when handling EHRs, requests should be met even more expediently, as there is no offsite storage access required. A timeframe of 3-5 business days would suffice for electronic records *only* requests.

Patients who are in a substance abuse disorder treatment programs have their records protected by confidentiality provisions under 42 CFR Part 2. The Part 2 records have a higher standard of protection. The higher standards on permissible uses by health care regulations have created barriers that restrict the use of data between healthcare providers who treat the patients. The Part 2 regulations were made in an era when electronic health records were virtually nonexistent. In today’s environment, hospitals and providers rely heavily upon electronic health exchanges and electronic health record systems. The health information on those systems is protected by HIPAA and for federal agencies and some Tribal entities, the data is also protected by certain provisions of the Federal Privacy Act of 1974 pursuant to the Indian Self-Determination and Education Assistance Act, and the Indian Health Care Improvement Act.

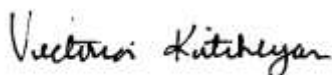
As mentioned previously, the interpretation of the Part 2 regulations should ideally align with that of HIPAA. The purposes of the Part 2 regulations are to prevent abuse and discrimination of those patients who wish to seek treatment for their substance abuse disorders. In order to effectively treat substance abuse disorder, the unreasonable prohibitions on the use of Part 2 records should align with the access and use provisions of HIPAA standards. Part 2 records should be treated in the same fashion as other health records under HIPAA, including the permissible uses for the purposes of treatment, payment, and health care operations. Aligning the Part 2 regulation interpretation or guidance with HIPAA will provide for seamless coordinated and quality of care by a patient's health care providers.

Recently many individuals and entities have recommended that Substance Abuse and Mental Health Services Administration (SAMHSA) align Part 2 regulations with HIPAA to broaden the allowable sharing of data for purposes of care coordination and patient safety. Toward this end, SAMHSA has made strides in doing so but there are still obstacles. For example, requiring consent forms to be signed for every disclosure that a patient sees a new treating provider whereas under HIPAA and the Federal Privacy Act have permission and routine uses that are flexible. It should be permissible for healthcare providers and entities to share health information for the purposes of treatment, including the patient records from those persons in a substance use treatment program.

The substance use disorder records and treatments should be held to the same level of privacy as all other health records. There is an issue of equal access where individuals with substance use disorder should have the same access to the benefits of increased care coordination as individuals without substance use disorder. More needs to be done to harmonize Part 2, HIPAA, and HITECH into a single uniform set of standards applicable for all health information, including substance use disorder treatment and payment. HIPAA is sufficient to protect patient privacy and part 2 is no longer necessary. Since Part 2 also predates the development of EHR and Health Information Exchanges (HIEs), and there is pressing need to reconsider these law and rules in light of more recent technological and legal developments. It is clear that healthcare entities have difficulty in complying with both part 2 and HIPAA as it has unintended and undue administrative burden and management issues across the continuum of patient care.

NIHB appreciates the opportunity to consult on the Office of Civil Rights Request for Information to improve care coordination in relation to HIPAA in the Indian Health system. We are prepared to provide technical assistance and answer any questions that you may have. We look forward to ongoing discussions. Please contact NIHB's Director of Policy, Devin Delrow, at ddelrow@nihb.org or at 202-507-4072 for any questions.

Sincerely,



Victoria Kitcheyan, Acting Chairperson National Indian Health Board