



USET

SOVEREIGNTY PROTECTION FUND

Washington, DC Office
1730 Rhode Island Ave., NW, Suite 406
Washington, DC 20036

Nashville, TN Office
711 Stewarts Ferry Pike, Suite 100
Nashville, TN 37214
P: 615-872-7900 | F: 615-872-7417

Submitted electronically via
consultation@hhs.gov

Robert F. Kennedy Jr.
Secretary
Department of Health and Human Services
200 Independence Ave. SW
Washington, DC 20201

Dear Secretary Kennedy,

On behalf of the United South and Eastern Tribes Sovereignty Protection Fund (USET SPF), we submit the following comments in response to the Department of Health and Human Services' (HHS) request for input on proposed changes to the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule. These comments do not address all proposed changes to the Privacy Rule, but focus on a few proposed changes that USET SPF finds concerning or unclear, particularly the proposal to relax requirements surrounding the disclosure of protected patient information to other individuals. We hope these comments are helpful as the HHS Office of Civil Rights (OCR) considers the final rule.

USET SPF is a non-profit, inter-tribal organization advocating on behalf of thirty-three (33) federally recognized Tribal Nations from the Northeastern Woodlands to the Everglades and across the Gulf of Mexico.¹ USET SPF is dedicated to promoting, protecting, and advancing the inherent sovereign rights and authorities of Tribal Nations and in assisting its membership in dealing effectively with public policy issues.

Revisions to Disclosure Regulations Must Prioritize Tribal Data Sovereignty

USET SPF is greatly concerned by several proposed revisions to the HIPAA Privacy Rule that we believe have negative implications for not only individuals' rights, but also for Tribal sovereignty over our collective protected health information. Tribal Nations must retain sovereignty over the health data of our citizens and communities. As sovereign Nations, we retain the right to govern the ownership, collection, and application of this data, and USET SPF is concerned that relaxing these regulations could undermine this authority.

¹ USET SPF member Tribal Nations include: Alabama-Coushatta Tribe of Texas (TX), Aroostook Band of Micmac Indians (ME), Catawba Indian Nation (SC), Cayuga Nation (NY), Chickahominy Indian Tribe (VA), Chickahominy Indian Tribe—Eastern Division (VA), Chitimacha Tribe of Louisiana (LA), Coushatta Tribe of Louisiana (LA), Eastern Band of Cherokee Indians (NC), Houlton Band of Maliseet Indians (ME), Jena Band of Choctaw Indians (LA), Mashantucket Pequot Indian Tribe (CT), Mashpee Wampanoag Tribe (MA), Miccosukee Tribe of Indians of Florida (FL), Mississippi Band of Choctaw Indians (MS), Mohegan Tribe of Indians of Connecticut (CT), Monacan Indian Nation (VA), Nansemond Indian Nation (VA), Narragansett Indian Tribe (RI), Oneida Indian Nation (NY), Pamunkey Indian Tribe (VA), Passamaquoddy Tribe at Indian Township (ME), Passamaquoddy Tribe at Pleasant Point (ME), Penobscot Indian Nation (ME), Poarch Band of Creek Indians (AL), Rappahannock Tribe (VA), Saint Regis Mohawk Tribe (NY), Seminole Tribe of Florida (FL), Seneca Nation of Indians (NY), Shinnecock Indian Nation (NY), Tunica-Biloxi Tribe of Louisiana (LA), Upper Mattaponi Indian Tribe (VA) and the Wampanoag Tribe of Gay Head (Aquinnah) (MA).

Because there is Strength in Unity

Importantly, this authority includes the right to informed consent on how a Tribal Nation's data, including protected health information about their community members, are used or shared with third parties.

As such, USET SPF is especially concerned with proposed revisions that would permit covered entities to disclose protected health information (PHI) to individuals other than the patient themselves in a variety of circumstances. We are also concerned that the proposed shift in standards from "professional judgment" to "good faith belief" could be potentially harmful to our rights to protect our health information. We acknowledge that HHS proposed many of these revisions in an attempt to mitigate harm or to ensure patients receive better care, but we fear that the proposed changes are too broad and might open the door to unintended consequences for patient safety and Tribal data sovereignty more broadly.

First, the proposed revision under the revised "good faith" standard that would permit a covered entity to disclose an individual's name and location within a healthcare facility when the individual cannot agree or object, if doing so is "in the best interests of the individual," seems potentially problematic for victims of domestic abuse or stalking – from which American Indian and Alaskan Native (AI/AN) women suffer disproportionately. This is especially concerning when taken in combination with the proposed revision that would allow a covered entity to disclose a patient's PHI without verifying the identity of the requester and their relationship to the patient. The proposed rule states the covered entity must have a "good faith basis for believing the requestor and the requestor's identity," but this seems insufficient to protect against potential harms. In addition, what would constitute a "good faith basis for believing" the requestor and their stated identity? If someone like a front desk staffer at a large hospital – who would have no knowledge of the patient or their circumstances – is given such a request, what information would this staffer have to make a good faith determination that the requestor is believable? Given the wide range of potential circumstances, it seems inadvisable to grant such broad discernment authority to disclose an individual's location and condition to anyone who can convince staff at a covered entity that they should.

USET SPF is also concerned by proposed revisions that would permit covered entities to disclose an individual's information to family members or other caregivers when the individual cannot agree to the disclosure because of absence, incapacity, or emergency circumstances, provided that the covered entity has a "good faith belief that the disclosure is in the best interests of the individual." While we acknowledge that there are likely scenarios where this is advisable, we worry that this change is a slippery slope toward infringing on individuals' right to make their own decisions regarding their own healthcare. More specifically, we worry that this may grant covered entities too much latitude to decide what is in an individual's best interests.

Relatedly, we strongly oppose revisions that would permit a covered entity to disclose the PHI of an individual who has decision making capacity in a "manner inconsistent with the individual's known privacy preferences (including oral and written expressions), based on the covered entity's good faith belief that the use or disclosure is in the individual's best interests" in any situations outside of an emergency circumstance, as suggested in the request for comments. The request asks if there are examples of instances in which a situation's facts or circumstances should or would outweigh an individual's preferences, but do not rise to the level of posing a "serious and reasonably foreseeable threat." USET SPF believes there are no circumstances in which it would be appropriate to override an individual capable of making the decision whether to release such information themselves. To do so has the potential to seriously infringe on the rights of adults to make their own decisions regarding their healthcare, and we worry that this has larger implications for populations such as American Indians and Alaskan Natives (AI/ANs). USET SPF is concerned that additional authority to override a patient's stated wishes would be dangerous and may discourage patients from seeking care. AI/AN populations have historically mistrusted the Western healthcare system due to centuries of paternalistic treatment, infringements upon our rights, and assertions of the validity of "modern" medicine over traditional and cultural healing practices. To allow

healthcare professionals greater latitude to ignore the wishes of patients in pursuit of patients' "best interests" has the potential to further perpetrate and exacerbate these issues.

The proposed rule HHS does acknowledge that the proposals "may raise concerns about unintended consequences where a covered health care provider is asked to disclose sensitive information to family members or other caregivers about individuals at risk of, or experiencing, abuse by the requesting family members or caregivers," and indicates that covered entities must incorporate an individual's risk of abuse in determining if releasing the information is in the patient's best interest. However, USET SPF contends that covered entities often would not have enough information to make such a determination, and the risk of disclosing information improperly is not insignificant. We also believe that HHS's assertion that, prior to disclosing the PHI of an incapacitated individual, covered entities must consider all circumstances, such as an individual's prior statements regarding privacy preferences, is similarly insufficient. In many instances, a provider would likely have no prior knowledge of an incapacitated individual's disclosure preferences; therefore, this consideration requirement does not protect against the most harmful possibilities created by this revision.

Tribal Nations have a responsibility to protect our citizens and prevent or mitigate harm to our communities. To do so, Tribal Nations must be able to exercise ownership over the protected health information of our citizens and restrict the access of non-Tribal individuals and entities to this data. HHS's own [Tribal Data Access Policy](#) recognizes this sovereign authority and acknowledges that "Tribal sovereigns exercise their rights of self-determination and self-governance over their members, territory, and resources," which necessarily includes the protected health information of our citizens and communities.

Minimum Necessary Standards Support Tribal Data Sovereignty and Protection

USET SPF is also concerned with proposed changes to exceptions from the minimum necessary standard requirements. The justifications provided for these revisions are based on the desire to improve care coordination and/or case management for patients. The revisions would create an express exception to the minimum necessary standard for disclosures to, or requests by, a health plan or covered health provider for care coordination and care management for individuals, essentially allowing providers to disclose PHI without having to make determinations on whether the requestor (such as a health plan's care coordinator) requested only the minimum necessary PHI for the purpose.

The current standard is the only requirement for covered entities to consider what information is reasonably needed for their purposes, and eliminating it has the potential to threaten patient privacy. This revision could create instances where a covered entity finds it more convenient to send a patient's entire record rather than parse out the minimum level of information needed to satisfy the request, which creates implications for patient privacy, as well as Tribal data sovereignty and our right to collective data privacy.. Tribal Nations must work across systems to protect against inappropriate access to and use of our data and removing the requirement to limit disclosures to the minimum necessary threatens our ability to protect our protected health information. USET SPF maintains that data protection standards should only be strengthened, not relaxed.

Additionally, USET SPF is concerned by the broad range of entities that could request PHI for the purposes of care coordination or case management. While we agree that ensuring individuals retain access to care, social services and their treatment plans, we believe that allowing any staff at entities like housing providers or nutrition programs creates risk to patient privacy, particularly if the minimum necessary standard requirements are loosened. These social services providers administer critical services to individuals receiving treatment for substance use disorders and mental health issues, but they do not require nor should they have access to a patient's entire medical record.

Conclusion

USET SPF appreciates the opportunity to provide comments on this critical topic. While we support certain revisions that will improve individuals' access to their own protected health information, we worry that the provisions we have discussed have the potential to threaten patient privacy and the sovereign right of Tribal Nations to govern the ownership and application of our citizens' data. We urge HHS to consider our comments and commit to ensuring HIPAA remains strong and focused on its original intent – to protect patients and their health information. Strong Privacy Rule regulations aid Tribal Nations in our responsibility to care for and protect our citizens and communities. Should you have any questions or require further information, please contact Ms. Liz Malerba, USET SPF Director of Policy and Legislative Affairs, at LMalerba@usetinc.org or 615-838-5906.

Sincerely,



Kirk Francis
President



Kitcki A. Carroll
Executive Director

