



September 13, 2010

Department of Health and Human Services
Office for Civil Rights
Attn: HITECH Privacy and Security Rule Modifications
Hubert H. Humphrey Building
Room 509F
200 Independence Avenue, SW
Washington, DC 20201

RE: RIN 0991-AB57

As president of the Society of American Archivists (SAA), I am writing to express the concern and consideration of our members about certain provisions of §160.103, Modifications to the HIPAA Privacy, Security, and Enforcement Rules Under the Health Information Technology for Economic and Clinical Health Act; Proposed Rule. America's archivists are professionals – working in institutions as disparate as hospitals and governments, churches and historical societies, businesses and universities – who daily practice balancing reasonable access to historical documentation and necessary protections of individual privacy. We serve historians and other researchers who create significant and sometimes policy-shaping work based on primary sources. We also serve the creators of those sources and the consumers whose health information comprises basic medical records.

We are aware of and concerned about the unprecedented risks to individual privacy that exist in the digital era. Never before has such an extensive amount of information been accessible, reproducible, and instantaneously distributable on such a large scale without the benefit of peer review.

Archivists are pleased to note that our concerns regarding the HIPAA Privacy Rule were taken into consideration in the proposed modifications to the rules.

In particular we support Section 164.502(f)—Period of Protection for Decedent Information:

Accordingly, we propose to amend § 164.502(f) to require a covered entity to comply with the requirements of the Privacy Rule with regard to the protected health information of a deceased individual for a period of 50 years following the date of death. We also propose to modify the definition of “protected health information” at § 160.103 to make clear that the individually identifiable health information of a person who has been deceased for more than 50 years is not protected health information under the Privacy Rule.

We concur with the Department of Health and Human Services, Office of Civil Rights (HHS/OCR) “that fifty years is an appropriate time span, because by approximately covering the span of two generations we believe it will both protect the privacy interests of most, if not all, living relatives, or other affected individuals, and it reflects the difficulty of obtaining authorizations from personal representatives as time passes.” We are encouraged that HHS/OCR took into consideration the testimony of archivists before the National Committee for Vital and Health Statistics (NCVHS) (<http://ncvhs.hhs.gov/050111mn.htm>). The current rule that protects health information in perpetuity is excessive, hinders valuable historical research, and prevents families from learning about the history of long-deceased family members. The proposed modification is more reasonable and will make it easier for general research on such topics as Civil War casualties or 19th century epidemics or doctor-patient relationships in the Gilded Age.

With respect to the proposed change in the Period of Protection for Decedent Information, we request an additional modification. We seek a definition of a date from record creation at which health information would no longer be considered protected. Suggestions as to when health-related records should no longer be covered by the HIPAA Privacy Rule have ranged from 75 years to 125 years from record creation. We support restricting access to 125 years. Presumably the proposed date would be selected to allow greater access to health information related to deceased individuals while still protecting the individually identifiable health information of living individuals. The question of the most appropriate date from creation still must be settled. Given that individually identifiable health information includes an individual’s entire lifespan from birth to death, the selected date must be long enough to ensure that the subject is deceased. Life expectancy in the United States currently is nearly 78 years. With documented life spans of ages into the 110s, a date that is closer to 125 years from creation would seem more prudent than 75 years. Restricting access to 125 years would also protect pediatric treatment records during a person’s expected lifetime.

With respect to Section 164.510(b)—Disclosures About a Decedent to Family Members and Others Involved in Care, we have questions regarding the proposed amendment § 164.510(b) to add a new paragraph (5), “which would permit covered entities to disclose a decedent’s information to family members and others who were involved in the care or payment for care of the decedent prior to death, unless doing so is inconsistent with any prior expressed preference of the individual that is known to the covered entity.” Would this amendment allow archival repositories to disclose a decedent’s information to family members during the period before 50 years beyond the decedent’s death or when the family members were not, or it is not known if they were, involved in the decedent’s care or payment for care? Archives increasingly receive requests from relatives, especially from subsequent generations, who are conducting a family history or medical genealogists seeking health information regarding a deceased relative that may have implications for their own health. Before the period of 50 years beyond the decedent’s death date has passed, relatives may require access to that information yet still desire to protect the decedent’s health information from the general public. Archives would like guidance regarding when it would be permissible to release decedent health information to family members. Should the nature of the family member’s relation to the decedent (blood relative, direct descendant, collateral descendant) be taken into consideration?

With respect to psychiatric records, we support the proposed rule that treats them in the same manner as other medical records. Currently under the rule, there are added protections for psychotherapy notes regarding use and disclosure, but presumably under the proposed rule those protections would cease 50 years after a patient’s death.

With respect to previously published information, we seek clarification regarding whether it is appropriate to exclude from the definition of PHI content that was previously published before the HIPAA Privacy Rule went into effect. Many archival repositories that are covered by HIPAA have, as a practical matter, accepted the interpretation that individually identifiable health information that has been published previously is in the public domain and therefore could be made accessible for further research and publication. A common example is previously published photos of hospital patients. As a practical matter it is usually not possible to identify a name or find the person to seek authorization for use or disclosure of the individual's photographic image. This interpretation – considering previously published health information as public and therefore not covered – is not stated explicitly in the Privacy Rule. As archivists strive continually to balance appropriate access with privacy protection, we would appreciate guidance on this matter.

Currently the Privacy Rule is not applied consistently across entities that may possess individually identifiable health information. The uneven application of HIPAA is frustrating and confusing. The proposed rule would extend the requirements of the HIPAA Privacy Rule to Business Associates of covered entities, which likely will include additional archives. Although this would ensure more even application of the HIPAA Privacy Rule, it could adversely affect access to entire collections (e.g., a collection of personal papers in a university historical archives that contain a small amount of health information that is not readily identifiable to archivists) due to the potential high cost and difficulty of removing/restricting the PHI. Therefore we do not support the expansion of the HIPAA Privacy Rule in this regard.

As archivists, we are pleased to see that HHS/OCR took into consideration research conducted by historians and other scholars to the benefit of the common good. We stand ready to inform and collaborate with legislators, policymakers, and the research community to define new standards and best practices for facilitating archival research while protecting individual privacy rights in a digital environment.

Thank you for your consideration of our concerns.

Sincerely,

A handwritten signature in cursive script that reads "Helen R. Tibbo". The signature is written in black ink and is positioned above the typed name.

Helen R. Tibbo
SAA President, 2010-2011