

**Society of American Archivists  
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**DRAFT Issue Brief: Health Information Portability and  
Accountability Act (HIPAA)**

**(Prepared by the Committee on Advocacy and Public Policy)**

This issue brief addresses the following priority within SAA's Advocacy Agenda, as adopted by the SAA Council in June 2012:

**The Public's Right to Personal Privacy in Certain Categories of Records**

An individual's right to privacy with regard to certain information—for example, records mandated by government, attorney-client records, and medical records—historically has been weighed against the public's right to information. Personal privacy should be respected throughout an individual's lifetime in appropriate ways. Documents recording private information about living Americans should be disclosed involuntarily *only* when disclosure accomplishes a greater public purpose.

**SUMMARY**

Adoption of the Privacy Rule under the Health Insurance Portability and Accountability Act (HIPAA) has had a major impact on archivists who are responsible for collections documenting the health sciences. The Privacy Rule is intended to protect the privacy rights of individuals, and it defines certain elements of information as Protected Health Information (PHI). Thus the rule governs access to information rather than access to records.

Interpretations of and the application of the HIPAA Privacy Rule to archival repositories vary widely based on a number of factors. In the absence of clear guidance and consistent best practices, some repositories can and do restrict access to collections that could be made available under the terms of HIPAA and state laws governing health information and medical records.

The issues related to access and use of archival collections documenting health and medicine are complex and present challenging ethical concerns. Archivists must seek solutions that balance individual privacy rights with access concerns.

## THE ISSUE

Several issues are in need of resolution at federal and state levels:

1. The change in the definition of Protected Health Information (in conjunction with adoption of the Final Rule in 2013) to exclude information on individuals who have been deceased for 50 years or longer was a step in the right direction. However, it is not always practical for archivists and researchers to determine, on a record-by-record basis, whether the individual(s) in question has been deceased for 50 years or longer.
2. Conditions of access to PHI for family members conducting medical genealogy research are unclear. Archivists are often unsure whether they can grant descendants access to PHI of their ancestors if the requestor is not the official personal representative of the deceased. The change in the Rule allowed covered entities to disclose a decedent's PHI to family members involved in the care of a patient, but appears to be limited to information involving the health of the patient during the period immediately pre- and post-death. Unresolved is the question of whether disclosures are permitted to family members for medical genealogy requests during the period from death to 50 years after death, when a personal representative would be required to authorize other disclosures.
3. Under the new amendments to the Privacy Rule (2013), archival repositories could be subject to Business Associate Agreements if they have health-care-related holdings that originated from a covered entity or a former member of its workforce – even if those collections were acquired before the HIPAA Privacy Rule went into effect. This means that many repositories that previously were not subject to the Privacy Rule now are – or might be. What constitutes a “Business Associate” is not entirely clear.
4. The question remains as to whether PHI that was published (for example, photos of patients in hospital annual reports or patient data in medical journal articles) before HIPAA went into effect is still considered PHI and restricted under the Privacy Rule.
5. The Privacy Rule is interpreted differently by different institutions. Archival repositories must follow the policies and protocols set by their parent institutions, which may or may not be “covered entities” under HIPAA. Parent institutions take a range of approaches, and thus policies and procedures vary widely from repository to repository. This situation confuses researchers and makes it difficult for the archives community to develop standardized practices. The recent change in the Privacy Rule continues to allow a covered entity to set policies that are more restrictive than HIPAA. As is the case with state medical records laws, the more restrictive rule prevails.
6. State medical records statutes differ from the federal law, and state records laws vary widely. States tend to place restrictions on records, whereas HIPAA protects information. The definition of the “medical record” varies from state to state, is vague in some cases, and can encompass documents outside of the unit medical record. The period of protection also varies widely. When a state law is more restrictive than HIPAA, the more restrictive rule prevails.

## THE SOLUTION

SAA believes that:

1. The federal government should amend the definition of PHI to exclude information in records created more than 150 years ago, but retain the exclusion of information on individuals deceased 50 years or longer. Information should be excluded from the definition of PHI either 50 years after the death of an individual or 150 years from record creation, whichever comes first. Adding this new provision would balance privacy and access concerns and address the challenge of whether archivists could provide access to records that contain health information about individuals whose death dates are not known. In all but a very small fraction of cases, the individuals involved will have been deceased for at least 50 years.
2. HIPAA should be modified/clarified to allow access to PHI for family members conducting medical genealogy research. Family members seeking medically necessary information in the file of a deceased relative should be given access to the file, regardless of other HIPAA regulations.
3. HIPAA should be modified to make clear the extent to which archival repositories that are not part of covered entities and that have health-care-related holdings are subject to Business Associate Agreements. SAA supports the development of guidelines, similar to those of the Covered Entity Decision Charts at <http://www.cms.gov/Regulations-and-Guidance/HIPAA-Administrative-Simplification/HIPAAGenInfo/Downloads/CoveredEntitycharts.pdf>, for a repository to determine whether it is a Business Associate under HIPAA.
4. HIPAA should be modified to make it clear that individually identifiable information and photographs that have appeared in publications are not considered PHI under the Privacy Rule.
5. A set of standardized “best practices” should be developed at the national level. Archivists at covered entities should have available to them standard protocols that could be presented to the HIPAA compliance officers at their parent institutions as the nationally accepted procedures for handling PHI in archival collections.
6. States should bring their medical records statutes in line with federal regulations to allow for standardization.

## BACKGROUND

The Health Insurance Portability and Accountability Act (HIPAA) was adopted by Congress in 1996. The U. S. Department of Health and Human Services developed the proposed Privacy Rule in 2002, and it went into effect on April 14, 2003. It was the first comprehensive federal law on access to and use of health information; the first general federal medical privacy law to extend rights of privacy beyond file unit of the medical record to individually identifiable health information in all types of file systems, documents, formats, and media; and the first federal law

to extend rights of privacy beyond health information of living individuals to health information of decedents. Although much of the Privacy Rule was needed to protect individuals' health information in the digital age, some aspects created compliance requirements that either were overly broad or left gaps in protection.

As archivists came to understand the implications of HIPAA for their repositories, they began to advocate for changes to the rule. In 2005, Nancy McCall and Stephen Novak testified to the National Committee on Vital and Health Statistics regarding the impact of the Privacy Rule on archives at covered entities.<sup>1</sup> They pointed out that the Privacy Rule applied only to archives designated as part of HIPAA-covered entities and did not apply to archives that are not part of covered entities but that also hold medical records and other related health information. They noted that HIPAA contained no provision for passage of time and questioned whether incidental health information related to long-deceased individuals required protection.

In July 2010, as a result of the HITECH ACT, the Office for Civil Rights of the U.S. Department of Health and Human Services (OCR) proposed changes to the Privacy Rule that took into consideration the concerns of archivists and historians, citing the testimony of McCall and Novak. Archivists and historians submitted comments both individually and through their professional organizations regarding the proposed changes.<sup>2</sup> On January 25, 2013, OCR published in the *Federal Register* its final rule to implement the privacy and enforcement provisions of the HITECH Act (the "Final Rule").<sup>3</sup> The Final Rule, which was effective on March 26, 2013, with a compliance date of September 23, 2013, modifies the HIPAA Privacy, Security, and Enforcement rules. Covered Entities have until September 23, 2014, to revise existing Business Associate Agreements in light of the changes in the Final Rule.

Personal privacy should be respected throughout an individual's lifetime in appropriate ways. Documents that record private information related to the health of living individuals should be disclosed involuntarily only when disclosure accomplishes a greater public purpose. The need for privacy rights to be extended to deceased individuals and the harm of disclosing their health information decreases over time. It is impractical for the staff of archival repositories to "de-identify" health information in all types of documents so that it may not be used to identify an individual. Further, for many types of studies, the removal of identifiers devalues the usefulness of the information and compromises the scope of research. It is impractical and not always advisable to seek out a personal representative for the long-deceased to authorize disclosure of individually identifiable health information. Archivists continue to advocate for a balance between reasonable access to historical documentation and necessary protections of individual privacy.

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<sup>1</sup> For Nancy McCall's testimony see: <http://www.ncvhs.hhs.gov/050111p6.pdf> . For Stephen Novak's testimony see <http://www.ncvhs.hhs.gov/050111p5.htm> .

<sup>2</sup> For the SAA comment by Helen Tibbo on September 13, 2010, see [http://www2.archivists.org/sites/all/files/SAA\\_HIPAA\\_091310.pdf](http://www2.archivists.org/sites/all/files/SAA_HIPAA_091310.pdf) . On November 27, 2007, SAA had submitted a letter to individual members of the Senate's Health, Education, Labor, and Pensions (HELP) Committee in response to introduction of S. 1814, The Health Information Privacy and Security Act of 2007, authored by Senators Kennedy and Leahy. See <http://www2.archivists.org/news/2007/saa-urges-congress-to-reconsider-hipsa-provisions>

<sup>3</sup> The final rule is available in full in the *Federal Register*: <http://www.gpo.gov/fdsys/pkg/FR-2013-01-25/pdf/2013-01073.pdf>

## **ADDITIONAL REFERENCE SOURCES**

Members of the Society of American Archivists [Science, Technology and Health Care Roundtable \(STHC\)](#) and the [Archivists and Librarians in the History of the Health Sciences \(ALHHS\)](#) have compiled a HIPAA resource page that includes links to the Privacy Rule and official resources from the Department of Health and Human Services, testimony by archivists on HIPAA, background articles, presentations, and other resources and tools for archivists. See <http://www.library.vcu.edu/tml/speccoll/hipaa.html>.