

# Too Much Privacy? OCR Proposes Easing Protections on Decedent Records

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By Kevin Heubusch

The HIPAA privacy rule generally conveys to individuals the same rights in death that they held in life. Two current proposals would change that, reducing the protections that covered entities currently must afford a deceased patient's record and easing access to decedent records by family, others close to the patient, and eventually, anyone.

Both amendments appear in the notice of proposed rulemaking on modifications to the HIPAA privacy and security rules mandated in the HITECH Act.

## Broadening Access beyond Representatives

Not all provisions in the privacy modifications stem from the HITECH Act. The Office for Civil Rights (OCR), which authored the rule, took the occasion to address a list of items it has been collecting since the privacy rule took effect in 2003. Although the proposals do not relate to ARRA, the proposed modifications are significant because of the impact on individuals and HIM operations.

Section 164.510(b) of the proposed regulation would allow covered entities to disclose protected health information (PHI) to family members and others who were involved in an individual's care or payment for care, regardless of whether the patient (or the state) has named them a personal representative.

Obtaining the records of decedents has been a frustration for many people, and managing the interplay of federal and state law has been a challenge for many HIM departments. As *Journal* writer Chris Dimick described in a story last year, HIPAA requires that covered entities release medical records to those people either appointed by the patient or deemed a personal representative under state law.<sup>1</sup>

Those restrictions can bar many people close to the individual from accessing the records. The Office for Civil Rights, which authored the draft modifications, has been aware of the situation. It writes, "We have heard concerns that family members, relatives, and others, many of whom may have had access to the health information of the deceased individual prior to death, have had difficulty obtaining access to such information after the death of the individual, because many do not qualify as a 'personal representative' under § 164.502(g)(4) [of HIPAA]."

OCR is proposing an amendment that 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.

Such disclosure would be permitted, but it would not be required. The modifications would not change the authority of a personal representative with regard to the decedent's protected health information.

Some states have already moved to broaden access. Wisconsin law now grants domestic partners the same authority over a patient's records as a spouse.<sup>2</sup>

OCR does not discuss how a facility would verify the identity of requestors who are not named by the patient, the courts, or state law. Most facilities require requestors to verify their identities, and it could be difficult for caregivers and others who lack a legal or formal relationship to verify their relationship to the deceased.

## Capping Rights at 50 Years

OCR notes that it has heard concerns since the publication of the privacy rule that it can be difficult to locate a personal representative to authorize the use or disclosure of a deceased person's PHI, particularly after the estate has closed. Archivists, biographers, and historians, it writes, "have expressed frustration regarding the lack of access to ancient or old records of historical value held by covered entities..."

Accordingly, OCR proposes an amendment that would require a covered entity to comply with the privacy rule with regard to protected health information of a deceased individual for a period of 50 years following the date of death.

The change would require a modification to the definition of protected health information, clarifying that the individually identifiable information of a person who has been dead for more than 50 years is not protected health information.

OCR suggests that 50 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 authorization for personal representatives as time passes."

The proposal will certainly please biographers and historians. It is unclear how individuals will feel. As lawyer Barry Herrin notes in Dimick's article, just because you are dead doesn't mean you want someone poking around in your record. A person who shielded his or her health information from others in life, Herrin says, may well want that information shielded in death, too.

OCR suggests that after 50 years "there may be few remaining individuals concerned with the privacy of such information," but that may be optimistic. It is not inconceivable for a child to survive a parent by 50 years, and many grandchildren will survive their grandparents by as many years. OCR's suggestion may appear even more optimistic in time, as more health records contain genetic information.

How many facilities will maintain records for more than 50 years is a different question. For the simple reason of storage space, most facilities will seek to dispose of paper records once their retention requirements have expired. Even digital information, which is far easier and cheaper to store, may not survive that long, given the rapid turnover in IT systems and the need to port data from system to system. Digital data may not be easily retrievable or readable after 50 years, even if it does reside on a backup tape or hard drive in a warehouse.

OCR requests comment on both proposals. Comments are due by September 13, and instructions for commenting are found in the published rule.

## NPRM Users Guide

In full, OCR addresses modifications to HIPAA on nine major subjects. Following is a guide to the topics covered within the NPRM and the section of the HIPAA privacy rule that they affect.

An overview of the rule's other provisions appears in this month's "[Word from Washington](#)" column. A longer outline identifying each section and its page number appears at [www.ahima.org/advocacy/arraprivacy](http://www.ahima.org/advocacy/arraprivacy).

The rule itself is available in the July 14 Federal Register (<http://edocket.access.gpo.gov/2010/pdf/2010-16718.pdf>). OCR will begin reviewing comments after the close date of September 13. It may make modifications based on its review and then proceed to a final rule, or if it desires additional comments, issue an interim final rule.

Page No.	Subject	HIPAA Section
40887	C. Business Associates	164.502
40887	1. Uses and Disclosures	164.504(e)

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40890	1. Sale of Protected Health Information	
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40894	E. Protected Health Information About Decedents	164.502(f) 164.510(b)
40894	1. Period of Protection for Decedent Information	
40895	2. Disclosures About a Decedent to Family Members and Others Involved in Care	
40895	F. Disclosure of Student Immunizations to Schools	164.512(b)
40896	G. Minimum Necessary	164.514(d)
40896	H. Fundraising	164.514(f)
40897	I. Notice of Privacy Practices for Protected Health Information	164.520
40899	J. Right To Request Restriction of Uses and Disclosures	164.522(a)
40901	K. Access of Individuals to Protected Health Information	164.524

## Notes

1. Dimick, Chris. ["Who Has Rights to a Deceased Patient's Records?"](#) *Journal of AHIMA*. Web exclusive. August 4, 2009. Available online at <http://journal.ahima.org>.
2. Ibid.

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