The 2010 Census and the HIPAA Privacy Rule

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Every ten years, the U.S. Constitution mandates that a full head count of the Nation’s population be counted.1 There was some initial debate among the founders of the country regarding whether, how, and on what timetable a census should occur,2 but they believed the process to be important to accurately determine congressional representation and thus, the census began in 1790.3 This year, the U.S. Census Bureau began mailing census forms to every household on March 1st.4 Information collected from the census helps determine a number of things, including state legislative and federal congressional districts and allocation of nearly $400 billion in federal and state funds distributed annually for health assistance, services for older adults, employment services, and schools.5 The only way to complete the census is by filling in the form using pen and ink or by speaking directly to a census employee who visits a business or household. For those individuals residing in long-term care hospitals, psychiatric facilities, or other healthcare facilities, the personal information required by the census may not be able to be obtained from the patient directly. In most cases it will be provided by an employee of the facility. Does such disclosure violate the patient’s privacy under the Privacy Rule of the Health Insurance Portability and Accountability Act (HIPAA)?6

Census Background

In 1954, Congress codified all previously-enacted laws related to the census into Title 13 of the U.S. Code. Although the Title does not specify which subjects or questions are to be included in the form, it directed that a full count of the population be conducted on or about April 1, 1980, and every ten years subsequent.7 In the intervening years the law requires the Census Bureau to gather statistics about the residents of the United States for use by Congress.

Failure, refusal, or providing false responses on the census can be met with a fine – although the amount has risen from the $20 imposed in the 1790s. Today, failure to respond can result in a $100 fine and providing false answers on the form can result in a

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3 Id.
However, it is doubtful that the Census Bureau will actually impose such fines, but the noncompliant individual or household may be greeted by a census employee to be interviewed as a result.

**HIPAA Privacy Rule**

The Health Insurance Portability and Accountability Act (HIPAA)\(^9\) was enacted by the U.S. Congress in 1996 with the intent to improve the portability and continuity of health insurance coverage, reduce health care waste and fraud, improve access to long-term care, and simplify the administration of health insurance.\(^10\) The legislation additionally required the HHS Secretary to issue privacy and security regulations if Congress did not enact them within three years of the law’s passage. When Congress failed to meet this deadline, HHS responded by adopting the *Standards for Privacy of Individually Identifiable Health Information*, also known as the Privacy Rule.\(^11\) The Privacy Rule aims to ensure that sensitive personal health information is shared for core healthcare-related activities while limiting inappropriate use and sharing of patient data.\(^12\) The Rule protects all “individually identifiable health information,” known as protected health information (PHI), held or transmitted by a covered entity or its business associate, in any form or media, whether electronic, paper, or oral.\(^13\)

**Information, Uses, and Disclosures**

An individual’s PHI is information, including demographic data, related to:

- the individual’s past, present, or future physical or mental health or condition,
- the provision of health care to the individual, or
- the past, present, or future payment for the provision of health care to the individual,
- and that identifies the individual or information for which there is a reasonable basis to believe can be used to identify the individual.\(^14\)

It includes common identifiers such as name, address, and date of birth – all of which is asked on the 2010 Census form.

Entities covered by the Privacy Rule include health plans, health care providers, and health care clearinghouses – each of which is responsible for ensuring compliance with the Rule by business associates.

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\(^12\) See *Summary of the HIPAA Privacy Rule*, supra note 10; Night, supra note 10.
\(^13\) 45 C.F.R. § 160.103 (2009).
\(^14\) Id.
Generally, a covered entity may not use or disclose an individual’s PHI without written authorization by the patient. However, some HIPAA regulations allow for verbal authorization by the patient to suffice and allow some instances when an individual’s PHI may be disclosed without his or her authorization. For instance, in order to maintain a directory of patients within its facility, an entity such as a hospital may, upon verbal agreement of the patient, disclose the individual’s name, location in the facility and general condition to “persons who ask for the individual by name.” Additionally, the law includes a very broad exception to the requirement that a patient authorize disclosure of his or her PHI. Pursuant to 45 CFR § 164.512(a), a covered entity “may use or disclose protected health information without the written authorization of the individual…to the extent that such use or disclosure is required by law and the use or disclosure complies with and is limited to the relevant requirements of such law.”

AHA Regulatory Advisory

Earlier this year, the American Hospital Association issued a Regulatory Advisory instructing hospitals and other healthcare facilities that they are required by federal law to cooperate in conducting the census. More specifically, the advisory noted that each hospital “is required to work with census staff to identify any hospital inpatients that have no other home and therefore must be counted as residents in” the facility. The federal laws cited in the advisory which requires healthcare facilities to disclose patients’ PHI are found in Title 13 of the U.S. Code.

Title 13

Title 13 of the U.S. Code is the authority under which the Census Bureau is conducting the 2010 Census. Like the HIPAA Privacy Rule, the Bureau is bound by federal law to not only ensure the privacy of basic identifying individual information but also the confidentiality of medical information connected with the name of a patient. Any business, including healthcare facility, which refuses to furnish the “names of the occupants” of the premises or to allow census employees access to the facility when “relevant to the census or survey being taken or made,” shall be fined $500. If an official with a healthcare facility refuses to “answer completely and correctly to the best of his knowledge all questions relating to his company, business, institution, establishment, religious body, or other organization, or to records or statistics in his

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21 Id. at p. 3.
official custody,” he shall be fined $500; if the individual provides false answers the fine increases to $10,000.24

Conclusion

Although the American Hospital Association in its Regulatory Advisory was not unequivocal in assuring healthcare facilities that no violation of HIPAA would result if patients’ PHI was provided to census employees, it noted that “HIPAA would seem to permit hospitals to use and disclose minimum necessary patient information” to comply with the information requested by the Census Bureau as contemplated in federal law found at Title 13.25

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