Enabling Patient Access: Data Stewardship Involves More Than Data Use and Disclosure

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Data stewardship is a hot topic. As this issue went to press, the Department of Health and Human Services was expected to publish a notice of proposed rulemaking on accounting of disclosures, an expansion of the HIPAA requirements mandated by the HITECH Act.

Rulemaking was also expected on a second set of privacy rule modifications from HITECH that will affect patient access to information. As the industry awaited these rules, HHS's Office for Civil Rights (OCR) levied a $4.3 million fine against Cignet Health in Prince George's County, MD, for failing to grant patients access to their health records.

Data stewardship involves more than managing data use and disclosure. This column examines HIPAA's other data stewardship obligations, the HITECH rules modifying the HIPAA privacy rule, and HIM's tasks for implementing the new rules and regulations.

An Obligation to Provide Access

Many think of the HIPAA privacy rule only in terms of the restrictions it places on the use of protected health information (PHI). They fail to remember that the rule also includes an obligation to make information accessible to patients.

Although health information belongs to the provider-who uses it for professional and business purposes-it is the patient's information. In effect, the provider is the steward of the patient's data.

Cignet Health was fined $1.3 million for failing to grant 41 individuals access to their health records within 30 days. According to OCR's report, Cignet did not respond to the individuals. The organization was fined an additional $3 million for failing to cooperate with the investigation, which OCR considered "willful negligence" of the HIPAA privacy rule.

It is unclear why Cignet Health refused to grant patients access to their information, but this is a situation beyond reason to most and certainly to OCR.

"Covered entities and business associates must uphold their responsibility to provide patients with access to their medical records, and adhere closely to all of HIPAA's requirements," noted Georgia Verdugo, OCR director, in a press release announcing the fine. "The U.S. Department of Health and Human Services will continue to investigate and take action against those organizations that knowingly disregard their obligations under these rules."

The notice of proposed determination and notice of final determination can be found at www.hhs.gov/ocr/privacy under "Enforcement Activities and Results."

New Rules Coming: More Access Faster

The HITECH changes to the HIPAA privacy rule are expected at any time. These modifications, coupled with the meaningful use EHR incentive program, require organizations to grant individuals access to their health information within shorter periods of time if the PHI is electronic-and potentially even if it is on paper.

Treatment plans, discharge summaries, and transfer data must be available to patients as they leave the provider's facility. Other information must be accessible to patients within days, and current information should be shared with the patient when requested during the admission or encounter.

In the absence of rulemaking, the industry lacks specifics on the new requirements. However, AHIMA has voiced its concern regarding organizations' ability to produce some of this information in today's hybrid record systems and without physician review.

Needless to say, the day is coming when patients will expect access to the data gathered and used in healthcare almost immediately. HIM professionals and clinical staff will be responsible for determining how data will be generated and collected and how to arrange the data for patient viewing and for importing the data into various consumer and post-discharge clinical reports.

Consumers are also concerned about granular privacy protections (e.g., protecting data elements). There is a wide range of opinions on what privacy protections are necessary for health information, from privacy at the data element to no privacy protections at all. The majority of consumers want their healthcare information to be available both for their clinical care and for secondary uses. A small minority want absolute control over their health information, even to the extent that the information should not be released in emergency situations.

There will be a compromise of some sort, and AHIMA is actively working with a variety of groups to ensure sensible management and control of health information while supporting an individual's right to control how his or her information is used.

HIM Data Steward Tasks

The new HITECH rules and regulations will require HIM professionals perform a number of tasks.

First, HIM professionals must work with clinical and IT staffs to implement the requirements while ensuring information is available to clinicians and others for appropriate use.

They must also communicate and discuss with patients the rights and options these rules provide and how their decisions to restrict access to their information will affect their care and the healthcare community's ability to use their information (de-identified as much as possible) for their good and the good of their family and neighbors. This task will require knowledgeable staff, whether HIM professionals or someone trained by an HIM professional.

We all change our minds, and we can expect that patients will, too. Any procedure, policy, or technology must be flexible enough to accommodate an individual's wish to change his or her privacy controls.

HIM professionals also have to consider PHI that will be sent or shared across a network. This sharing may be point-to-point exchange, such as that offered by ONC's Direct Project; through a local, state, or even national health information exchange; or in an accountable care organization. No matter what type of data exchange, HIM professionals must ensure the right controls and access are in place and understood so that individuals can make decisions on whether to allow such an exchange.

For this reason, AHIMA has urged its members to become engaged in the various network alternatives being developed. These programs will affect HIM professionals' future work and obligations. It is not too late to add your expertise to the mix.

The HIM profession has consistently recognized its role in supporting patient rights to health information while ensuring clinicians and other users of health information have healthcare data whose integrity cannot be questioned. These stewardship obligations are not new, but they are becoming more complex as the rights of the patient and the needs of the data user may be in conflict.

HIM's data stewardship responsibilities include informing and educating these parties and developing a means to expedite the stewardship processes for the good of all.

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