Providing Patients with Meaningful Choices: Consumers Need Guidance on When (and When Not) to Release PHI

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By Julie Dooling, RHIA

HIM professionals have a rich and proud history serving as custodians of the health record, with solid experience and knowledge in process, policy, and procedure surrounding the management and disclosure of health information. In the recent past, this information was confined to the inside of a facility or organization. Today, the industry is entering a new environment where components of the health record are being shared and exchanged widely outside of the proverbial four walls.

The evolving health information exchange (HIE) environment brings new challenges and new ways to use and exchange health information. Healthcare organizations are poised to share high volumes of protected health information (PHI) in the years to come, and patients will need education on making choices when it comes to deciding who can access their PHI.

PIN Guidance Issued to State HIEs

In 2012, the Office of the National Coordinator for Health IT (ONC) introduced a Privacy and Security Program Instruction Notice (PIN) for state-level HIEs. The guidance set forth by ONC builds upon recommendations from the Health Information Technology Policy Committee (HITPC) and the ONC report "Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information."[1]

The notice outlines content required to establish policies and practices when exchanging information through an HIE. The goal of the guidance is to provide a common set of privacy and security rules that create trust among providers and consumers. ONC and HITPC agree "that when providers give patients a choice about whether their health information can be shared, it should be a meaningful choice."[2]

According to ONC, providing patients with a "meaningful choice" means that the healthcare professional or provider "ensures patients understand how and with whom their provider can share their information and the impact of their choices."[3]

For instance, in one of the seven PIN domains, the "Openness and Transparency" section calls for these attributes to be included in policies, procedures, and technologies that pertain to consumers and, in particular, their individually identifiable health information.

HIM professionals should be aware that the PIN calls for HIEs to create and distribute a notice of privacy practices (NPP) that describes why individually identifiable health information is collected, how it is used, and to whom and for what reason(s) it is disclosed.

Guidance states that the notice should:

1. Be simple, understandable, and at an appropriate literacy level
2. Highlight, through layering or other techniques, the disclosures and uses that are most relevant (for example, the notice of privacy practices could have a summary sheet followed by a description of actual use and disclosure practices)
3. Adhere to obligations for use of appropriate language(s) and accessibility to people with disabilities

Informed Consent Hinges on Trust

There is no doubt that the success of informed consent hinges on a relationship of trust, where the focus will need to be placed on bridging the communication gap with healthcare consumers. Some challenges, such as how to handle sensitive data, may seem daunting from a technical and operational viewpoint and will likely take time to define an associated best practice.

It is estimated that 90 million Americans have difficulty understanding health information.[4] In order to provide healthcare consumers with "meaningful choice," HIM professionals must assist and guide consumers and healthcare facility staff in creating and maintaining health literacy programs and practices-including policies and procedures, comprehensive education, and training and awareness programs.

The health literacy of these materials should be at a simple and understandable level and provided in the various languages that are applicable to the healthcare organization's patient population. According to Anjum Khurshid, PhD, MD, MPAFF, director of the health systems division and principal investigator at Crescent City Beacon Community, Louisiana Public Health Institute, the material development is iterative and "not just a one-time process." Khurshid also notes that the materials should be developed at about a fourth to sixth grade reading level for ease of understanding. For a population being served mainly through community health centers, health literacy is an important consideration when trying to develop materials that patients can read and understand.

When developing these tools, collaboration and coordination should extend to the larger healthcare community. Special consideration should be given in instances where patients cross state lines on a regular basis to seek care.

Educate Patients Now

While the logistics of how HIEs will ultimately operate at a national level may not yet be certain, HIM professionals can begin to teach consumers meaningful education about consent rights and encourage them to get involved. The goal is to provide consumers with the best possible explanation of their rights and choices when it comes to their health information.

Notes

1. ONC. "Nationwide Privacy and Security Framework for Electronic Exchange of Individually Identifiable Health Information." December 15, 2008. http://www.healthit.gov/sites/default/files/nationwide-ps-framework-5.pdf.
2. Marchesini, Kathryn. "Meaningful Choice: Patient-Centered Decision Making in Electronic Health Information Exchange." October 3, 2012. http://www.healthit.gov/buzz-blog/privacy-and-security-of-ehrs/meaningful-choice-electronic-health-information-exchange/.
3. Ibid.
4. AHIMA. "What is Health Literacy?" myPHR.com. http://myphr.com/HealthLiteracy/default.aspx.

Julie Dooling (julie.dooling@ahima.org) is a director of HIM practice excellence at AHIMA.

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