Educating Consumers on Their Privacy, Security Rights

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AHIMA has continually recognized the importance of consumer engagement in healthcare through education and advocacy. Through its partnership with other patient advocacy organizations and investments in its own consumer-focused initiatives, AHIMA has demonstrated its commitment to helping consumers better understand the healthcare system.

AHIMA's support of public websites such as MyPHR.com, ShareCare.com, and promotion of the Blue Button Initiative shows that AHIMA's advocacy is patient-centered and focused on improving care outcomes. This article will highlight the association's latest activities and bring attention to AHIMA's Consumer Health Information Bill of Rights.

AHIMA Partnering with Industry Groups for Change

In the past few years, AHIMA has forged partnerships with like-minded consumer-centric organizations to boost awareness of how health IT can be used to improve healthcare, as well as develop its own resources. Some of those resources and alliances include:

- **MyPHR.com**, a website from AHIMA offering information on how to access medical records, as well as how and why to start a personal health record (PHR). The website includes information on common privacy myths, how to avoid medical identity theft, and how to choose a PHR vendor. The website also offers guidance on health literacy, as well as tools and tips for navigating the nation's complex healthcare system.
- **Sharecare**, a health and wellness engagement platform that provides consumers with personalized information, programs, and resources to improve their health. It provides information to the site's users based on their responses to the RealAge Test (the company's health risk assessment tool) and offers a clinical decision support tool, AskMD, where consumers can find experts to answer health questions.
- **The Blue Button Initiative**, a national program that allows patients to view and download personal health information. The program includes pledges of support from many stakeholders to make it easier for individuals and their caregivers to have secure, timely, and electronic access to their health information. Healthcare organizations like providers, hospitals, payers, and retail pharmacies that manage or maintain individual health data pledge to provide a secure portal from which an individual can download personal health information.

Privacy Bill of Rights

As health information management (HIM) professionals know, the HIPAA Privacy Rule provided individuals the right to be informed of the privacy practices of their health information and to be informed of their privacy rights. Covered healthcare providers are required to develop and distribute a notice that provides a clear explanation of these rights and practices. As a result, Notices of Privacy Practices are a routine patient communication in healthcare settings today.

In May 2015, AHIMA published the "Consumer Health Information Bill of Rights—A Model for Protecting Health Information Principles." This document focuses in large part on patients' rights to privacy and security of their health information. AHIMA created the Consumer Health Information Bill of Rights "for the purpose of educating all people about the protections related to their personal health information."[1]

Consumers have the right to:

1. Look at their health information and/or get a paper or electronic copy of it.
2. Accurate and complete health information recorded by their care providers.
3. Ask for changes to their health information.

4. Know how their health information is used or shared and who has received it.
5. Ask for limitations on the use and release of their health information.
6. Expect that their health information is private and secure.
7. Be informed about privacy and security breaches of their health information.
8. File a complaint or report a violation regarding their health information.

Although HIM professionals are well-versed in existing legislation and regulations that address privacy and security, it is still common for consumers to be unaware of the protections afforded them under the law. While HIPAA requires that providers notify patients about their rights through Notices of Privacy Practices, patients may not take the time to review their rights or may not fully comprehend their application when faced with actual privacy or security issues. The information can also be confusing to the average consumer.

HIM's Role in Engaging Consumers

There are many initiatives HIM professionals can introduce to make patients more aware of their privacy and security rights:

- Posting AHIMA's Consumer Health Information Bill of Rights in patient waiting areas.
- Creating attention-grabbing posters illustrating common privacy and security problems.
- Including information regarding patient privacy rights with the organization's public broadcasting and advertising announcements.
- Conducting regular patient education sessions or adding privacy and security topics to regular patient-facing sessions (such as childbirth classes and group therapy sessions).
- Implementing a privacy and security hotline to answer patient questions about their privacy rights.
- Posting regular privacy and security tips on the organization's main website.
- Distributing reader-friendly, attention-grabbing versions of the Notice of Privacy Practices throughout the organization for patient convenience.
- Explaining privacy protections when using patient portals.
- Conducting educational sessions for workforce and providers to further strengthen the understanding of appropriate privacy practices.

Patients can also be directed to the Code of Federal Regulations, 45 CFR§164.524, at the Government Printing Office, to read about their rights to access their health information under HIPAA: www.gpo.gov/fdsys/pkg/CFR-2011-title45-vol1/pdf/CFR-2011-title45-vol1-sec164-524.pdf.

The US Department of Health and Human Services (HHS) website, HHS.gov, also provides information about patient rights to privacy and security of health information by searching topics such as "HIPAA," "privacy," and "confidentiality." HIM professionals should share this information with healthcare consumers at every opportunity.

HIM professionals have all heard the phrase: "An educated consumer is our best customer." The more communication and education health information professionals can provide about privacy and security, the better educated the patient population will be about their health information rights. As noted above, numerous outlets are available for this communication and education.

Patients aware of their privacy and security rights will promote and demand accurate and timely information, which is maintained and released appropriately. These efforts will contribute toward ever-stronger protection of patients' rights to privacy and security.

Note

[1] AHIMA. "AHIMA Consumer Health Information Bill of Rights." May 2015.

Reference

Kadlec, Lesley et al. “HIM Best Practices for Engaging Consumers in Their Overall Healthcare.” *Journal of AHIMA* 86, no. 9 (September 2015): 50-56.

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