Engaging Health Consumers with Health Information

Save to myBoK

By Dan Rode, MBA, CHPS, FHFMA

This month's *Journal of AHIMA* takes a closer look at the importance of consumer engagement. HIM professionals have an obligation to the consumer to help maintain the integrity, security, and accessibility of health data and support the consumers' right to access their information in a secure manner. AHIMA is working on several projects to continue the profession's commitment to the evolving role of HIM professionals as stewards of health information in today's US healthcare industry.

AHIMA's commitment to consumer engagement with health information goes back many years, but it was not until 2011 that a practice council was appointed specifically to take on the issue. In the past year, the AHIMA Consumer Engagement Practice Council developed a guide to medical records and an enhanced approach for working with the Office of the National Coordinator for Health IT (ONC) on consumer access to health records.

myPHR Changes Ahead

One of the more noticeable changes underway is the metamorphosis of AHIMA's consumer-facing website, www.myPHR.com. Over the next several months, members will see the changes taking shape. In addition to a new website name, the site's purpose will grow from addressing only personal health records (PHRs) to a broader focus on consumer-related issues such as health information access, use, rights, and responsibilities. Other topics addressed include privacy and security, tools to understand health records and information, and the role of HIM professionals in health data stewardship. AHIMA's initial efforts will continue into 2014 with the website's official full launch.

During this time the content of the website will be updated and expanded as noted. The landing page currently displays a new video that was developed by the AHIMA Consumer Engagement Practice Council and AHIMA staff to explain the importance of having access to one's health information. The same video has also been shown on American Airlines flights.

AHIMA is developing a new consumer education project that will have component state associations and volunteer members delivering the association's message to communities across the nation.

For years several AHIMA practice councils and staff have been dedicated to getting consumers actively involved with their personal health information and their healthcare. AHIMA responses to federal requests for comments and notices of proposed rulemaking (NPRMs) have routinely included a consumer perspective. The engagement of the patient in care and opening up information access to consumers is a culture change for many professionals in the industry, and HIM has a role in helping facilitate this change.

Patient-Centered EHR Standards

AHIMA has also emphasized a focus on the needs of patients by working to ensure that standards are developed that help provide understandable data from electronic health records (EHR), as well as the ability for EHR information to be shared not only with the patient but also with caregivers and other personal providers. AHIMA chaired a Health Level Seven (HL7) workgroup to develop a standard that allowed EHR information to be shared with personal health records. AHIMA staff have also actively participated in the development of standards that allow for EHR information to be passed to downstream healthcare providers, and discharge information to be passed to patients.

Standards work continues to address the need for confidentiality and security in the form of data segmentation and data exchange. AHIMA has also contributed to this work in the development of practice briefs and other guiding documentation that highlights and demonstrates best practices in using multiple standards to accomplish various HIM functions and duties related to health information accessibility.

Standards and interoperability issues are expanding to mobile devices. The speed of technology development in many cases is moving faster than that of healthcare providers' technology. One of the roles HIM professionals must be prepared to handle is bridging the resulting gap between providers and patients until their own technology is ready to deliver data to the consumer.

Standards and usage are also a focus of ONC and its Health IT Policy and Standards Advisory Committees. AHIMA is working hard to ensure that members of the two committees' workgroups understand the needs of the consumer and the fundamental best practices necessary for meeting certification criteria of the "meaningful use" EHR Incentive Program. AHIMA and association members must help these groups come up with a rational consensus that allows the industry to move forward, be flexible, and learn from its mistakes.

Recently ONC and the Centers for Medicare and Medicaid Services announced that development of stage 3 meaningful use proposed rules will be delayed until 2014. No "one size fits all" solution or method exists for implementing meaningful use. HIM professionals must be actively engaged in the development and implementation of the meaningful use program, and help their organizations and the government monitor successes and failures in order to develop an effective learning system.

HIM Serves as Patients' Data Protector

HIM professionals' commitment to patients and the integrity of their data has become a focal point when working with clinicians and other allied health staff. All providers have come to realize that health data touches every source, assembly, and storage area, and is used in every admission, encounter, or episode of care. The obligation of data integrity and confidentially goes beyond the HIPAA privacy and security rules. Despite maintaining all of the privacy and security aspects of HIPAA and other rules, if the data itself cannot be trusted, then the obligation of HIM professionals to the patient falls short and potentially puts a consumer's health at risk.

In addition to the importance of working to advocate for consumers on an individual level, there is also an obligation to the individual as part of a larger community. Many current healthcare endeavors-such as public health research and quality reporting-assume a willingness on the part of the consumer to participate in order to contribute to population health improvement. Comments made at a number of hearings and meetings in Washington, DC suggest that most of the US population (more than 90 percent) do not mind sharing their healthcare data. There still exists a need for education to help consumers understand what information is shared and the methods used. The needs of those consumers who do not want their information shared need to be addressed as well.

Stepping Up as Educators

During AHIMA's personal health record outreach, AHIMA members often reported that consumer questions were reaching beyond basic PHR queries to privacy and confidentiality issues, as well as attempts to gain a better understanding of the information received. Many consumers are overwhelmed as the development of technology related to health information continues to move at a rapid pace, and relevant education is limited-especially considering the amount of time HIM professionals must also spend keeping up with technological developments for their own organization as well as the various government mandates and initiatives currently underway.

HIM professionals are ideally positioned to reach out to consumers, filling the educational role that will help to improve health information literacy and bridge the gap in professional understanding of EHR uses and their interface with other practitioners and patients. It is up to the HIM profession to reach out to patients and improve their understanding of electronic health records. The AHIMA Consumer Engagement Practice Council has rolled up their sleeves to provide informational materials for consumers and professionals alike to bridge this gap in education and understanding. The council will also continue to further develop the HIM professional's role as that of data steward, working for the better health of consumers and communities alike.

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