Consumer Health Information Bill of Rights Advancing Public Good

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By Vera Rulon, MS, RHIT, FAHIMA

Walk into any midsize medical practice and you'll see firsthand that technology is reshaping healthcare. The move to electronic health records has gone beyond the tipping point, while mobile technologies are revolutionizing information sharing. Yet despite the array of technology at providers' and consumers' disposal, both are confronting a core issue of trust, working to find the balance between gathering information and protecting it, allaying fears of disclosure but trying to engage people to take action to protect their health.

The duties of a free society demand the protection of rights that people—be they consumers, patients, and/or caregivers—have to gain access to their personal information, to be confident that it is secure and private, and to ensure that incorrect information is corrected. Further, patients' rights encompass personal control over how information is used and who is permitted to read it and use it. Healthcare providers who respect these rights and raise awareness of them build trust with patients and create an environment where patients become more engaged in their care.

Bill of Rights Provides Guidance

In order to enable such consumer engagement AHIMA has updated its Consumer Health Information Bill of Rights, which is available in both English and Spanish. This aligns with the core AHIMA strategy of Public Good, which states:

"Empower consumers to optimize their health through management of their personal health information. This includes advocating or advancing progress toward the day when all consumers can securely transport their health information with them, no matter where they may travel in the world, ensuring timely access to their own information, where and when it's needed."

The purpose of the Consumer Health Information Bill of Rights is to educate the public on the protections in place to secure their personal health information and the policies that ensure its accuracy. The Bill of Rights explains every individual's right to access and expect protection of their protected health information (PHI) as well as the expectation that appropriate actions will be taken when these rights are abridged.

These rights work hand in hand with another tool called "Understanding Your Medical Record" that is available on AHIMA's MyPHR.com website. While a consumer accessing their record is an important first step, knowing what is in medical records helps the consumer connect to the value of health information.

There are many benefits of patients accessing their personal health information. In order to participate in decision making regarding their care, patients should know and understand what their healthcare data mean. For example, diabetics should understand which blood sugar levels put them in danger, just as people managing heart conditions should know when their cholesterol readings are too high.

Also, when a patient comes into the doctor's office and is well informed about a condition, that patient can participate more fully in shared decision making on health matters. This enables the patient to understand the potential courses of treatment, express values and preferences, and increase the chances that the treatment will succeed.[1]

One area where shared decision making is optimally applied is in evaluating and deciding on treatment options. Personal preferences, levels of risk, and potential outcomes are all considered in partnership with healthcare providers in order to make the best choices for the patient. Once the decision on treatment options is made, patient access and further contributions to personal health information helps monitor the outcomes and, hopefully, cure or recovery.

Another benefit of giving patients access to health information is it improves the accuracy of health data. Several studies have shown that patients contributing to or correcting their personal health information can improve the quality of that information. In one instance, a study reviewed the presence of documentation of depression risk within patients' longitudinal medical record (LMR) problem list. Patients were invited to complete a depression survey. Approximately three quarters of the patients whose answers indicated a high or moderate risk did not have depression on their LMR problem list.[2]

HIM professionals can use the Bill of Rights to empower patients in their workplace and in their community. Below are some suggestions on how to do this.

Using the Bill of Rights at Work

- **Post the Bill of Rights in your HIM department.** Place copies of the Bill of Rights for patients, their caregivers, and healthcare providers to take with them. This will help raise awareness of individual rights. Be sure to have the "Understanding Your Medical Records" brochure on hand as well.
- **Train staff on the Bill of Rights.** As awareness efforts about the Bill of Rights continues, many staff members will have questions. Staff should be well versed in these rights, both for themselves and for any questions that may arise from patients and healthcare providers.
- **Share with others outside HIM.** Raise awareness in other areas of your organization. This way, as you share the Bill of Rights from administration to front-line workers, there will be a clear understanding of what rights patients have within and outside your organization.
- **Actively practice the Bill of Rights.** Be sure to practice its concepts in your daily work, especially when you receive a request for personal health information. Develop a process in your organization to follow up on specific issues raised in relation to the Bill of Rights.

Using the Bill of Rights in Your Community

- **Distribute copies of the Bill of Rights.** You can leave copies of the Bill of Rights and "Understanding Your Medical Records" brochure in public venues such as libraries and community centers.
- **Agree to present at a health-related meeting, a community event, etc.** The Bill of Rights lends itself well to an educational program at community meetings, senior centers, libraries, and other gathering places. Look to materials from AHIMA, such as "Understanding Your Medical Records" brochure, to share with the public.
- **Educate your family and friends.** Talking to family and friends about their personal health information rights is a good strategy to build awareness.

Research Work Also Must Ensure Privacy

While the Consumer Health Information Bill of Rights doesn't discuss donation of data for research, this is also an important topic. Clinical trials are a good way to contribute to medical research, and increasing numbers of researchers are examining real world data to find new treatments and evaluate the effectiveness of existing ones. Data that are donated for research purposes are protected. As the Bill of Rights states, personal privacy must be ensured. And most people—91 percent of those surveyed in a recent poll—are willing to share their personal data for research, especially if the information is used for disease prevention, research, or to help improve quality of care.[3]

HIM Should Personally Access Their Own Records

Both the Consumer Health Information Bill of Rights and "Understanding Your Medical Records" are tools that can help empower people. Remember, HIM professionals are patients too. As such, having access and control over personal health information is a key to being an effective team member.

Notes

[1] Charles, Cathy, Amiram Gafni, and Tim Whelan. "Shared Decision-Making in the Medical Encounter: What Does It Mean? (Or, It Takes at Least Two to Tango)." *Social Science and Medicine* 44, no. 5 (1997): 681-692.

[2] Wuerdeman, Volk et al. "How Accurate is Information that Patients Contribute to their Electronic Health Record?" AMIA Annual Symposium Proceedings, 2005.

[3] Lipset, Craig. "What If You Could Donate Your Data For Research?" GetHealthy StayHealthy. May 27, 2015.

References

AHIMA. "Understanding Your Medical Record."

Rulon, Vera. "Your Rights Regarding Your Personal Health Information." GetHealthy StayHealthy. September 11, 2014.

Download
Access the Full Consumer Health Information Bill of Rights

Read and download the updated 2015 AHIMA Consumer Health Information Bill of Rights in the HIM Body of Knowledge. A Spanish language version of the document is also available.

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