Personal Health Information: Reframing the Dialogue

Save to myBoK

by Linda L. Kloss, RHIA, CAE, FAHIMA

We all believe that healthcare can be more effective when people are armed with trusted information about their needs and best options. This premise is driving the urgent push for personal health records (PHRs) and quality and cost transparency.

Information Views and Practices

The phrase *personal health record* describes the consumer's view of their own or their family's health information. It's fine to use the term *record* so long as we understand that the information content varies depending on the type of PHR. For example, PHRs that are fed from EHRs are likely to have a more extensive clinical data set than ones sponsored by health plans. A health plan-sponsored view may have descriptive information such as dates, billing codes, lab results, and medications for episodes of service across providers. In "Piecing together the PHR" the *Journal's* managing editor Kevin Heubusch compares and contrasts the range of data views.

When managing my personal financial information, I use online services from the bank, my Quicken accounts, and reports from other services. I even use my check register to keep my current balance close at hand. I expect that we will learn to use personal health information in much the same way. We may use a PHR offered by our provider as a trusted source of clinical assessment and tests and a communication link with our physicians. The health plan view may be used to track dates of service and check the status of claims and deductibles.

While there will be different views, the quality and usefulness of the information and its security and confidentiality will be absolute prerequisites for all of us. Today, however, we are not ready to assure the public that there are effective information management standards and practices in place for PHRs.

Consumer Choice and Service

Just as we are not prepared for standards-based PHR information management, we are also not prepared to deal with customer care issues that go along with people trying to make sense of information from providers, employers, and insurers.

In "Patient-centered Design" Margarita Morales Rodriguez, Gail Casper, and Patricia Flatley Brennan describe how user-centered design affects the development of PHRs based on user needs, wants, skills, and preferences. We are used to having a choice in our tools, services, and technologies, and PHRs will be no different. Effective design that simplifies and educates will be essential to customer satisfaction. Still, some level of services will be necessary to support the overall value of personal health information solutions.

In "A Public Life" Irene L.E. Mueller, Mary Teslow, and Ann Hallyburton present a model for consumer health information services. It contrasts the roles of HIM professionals and medical librarians to help consumers with personal health information and resources. It also suggests the need for a new level of collaboration between these two groups.

Ellen Jacobs reminds us that HIM professionals have always been advocates for patient access to their information and guardians of its confidentiality. In "The HIM Role in the PHR" she describes how these values may expand into new roles for HIM professionals who choose to be information advocates. Skye K. Schulte offers solid advice on change and culture in "Avoiding Culture Shock."

If this year is anything like the last, expect to see a sharp increase in PHR initiatives and a sharp escalation of the public debate about standards, practices, and service to support consumers who are learning to use and trust their personal health information. We who manage the information must take these new responsibilities very seriously.

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