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Consumer Health Information Advocate: New Role for HIM Professionals

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Leslie: The concept of a “consumer-driven health system” is finally emerging in the public consciousness. With health care costs continuing to soar and consumers demanding greater flexibility, many employers are involving employees more in decisions related to their health coverage, instituting consumer-driven health plans. The idea behind these plans is to enable the consumers to have a real voice in how and where to spend the health care dollars available to them.

Patty: The jury is still out on the best approach to consumer-driven health plans. A variety of approaches are being tried and are being studied. For example, employers may select fully defined contribution plans where employees use vouchers to go out and purchase their own insurance; or, they may offer tiered plans that allow employees to choose from among plans of varying costs. Medical savings accounts (MSAs) are another example of a consumer-driven health plan that is getting much attention today. We don’t know which one of these health plans will become the most popular, but we do know that the need for all stakeholders to take responsibility for controlling health care costs is propelling us toward a new way of funding health coverage, one with greater consumer participation.

Leslie: Along with the emergence of consumer-driven health plans, the movement toward an electronic health record (EHR) and its companion, e-HIM™ continues to progress. On the surface these initiatives may seem unrelated, but they are all part of the solution to controlling rising health care costs. Most important, they all include a prominent role for consumers.

Patty: I agree. If consumers are to make responsible choices, they must be making informed choices. The public’s health literacy will have to improve. Consumers will need to know more about their own health care and be more involved in managing it. Having access to, and understanding their personal health information, will be an important part of the consumers’ knowledge base in a consumer-driven health system.

Leslie: Then it seems to me that health information management (HIM) professionals must start giving some serious thought to the emerging e-HIM role of “Consumer Health Information Advocate.”

Patty: In last month’s column, “It’s All About Leadership,” we talked about how challenging it is going to be to develop some of the new knowledge worker roles because we really don’t know exactly what they will look like yet. A consumer health information advocate will certainly meet our definition of a knowledge worker, one whose primary work product consists of information. Beyond that, the vision is still a little fuzzy.

Leslie: Like other e-HIM roles, I am sure the consumer advocate will have more than one responsibility. One vision is of consumer health information advocates teaching people how to use the new EHR systems available to them through their local health care organization.

Patty: What you are suggesting can be an endeavor of considerable magnitude. Consumers will first need basic computer skills and have access to computers. While a large segment of Americans have home computers, let's not kid ourselves. The digital divide still exists, and significant numbers of people do not own computers, nor are they computer literate. HIM professionals will need to decide if teaching people how to use computers is part of their new mission as consumer health information advocates.

Leslie: The second important aspect of the consumers' need for knowledge is for them to learn basic HIM skills. These skills include at minimum how to access their personal health information electronically, how to protect the privacy of their information, and how to release information to providers, other entities or individuals to whom they want to authorize access.

Patty: You pose yet another very challenging goal. Do you think that health care organizations will be able to fund this kind of education for the consumers?

Leslie: Funding is the biggest obstacle to all of the actions involving EHRs, but there are many stakeholders and mounting recognition of the long-term value that will be realized by not only implementing the vision of the EHR but also by realizing maximum benefit from an EHR when it is implemented.

Patty: As consumer health information advocates, we also will need to help people see their health records as part of an interactive process that they engage in with their health care providers. The HL7 EHR Systems Functional Model: White Paper published by Health Level Seven Inc. and available on the Web site, www.hl7.org states "The HL7 EHR-S Functional Model and Standard documents key functions that will enable patients to play an important role in their own health care." It is envisioned that EHR systems will provide decision support tools for self-health management, and make it feasible for patients to update their health records and better communicate with their providers. The concept of "self-health management" is central to evolving toward a consumer-driven health system.

Leslie: Achieving the self-health management aspect of the EHR will be a significant change in mindset for many providers and consumers. First, the American public has always relied on the health providers to create and maintain medical records, and control access to them. Most people have little or no clinical information that they maintain for themselves in any systematic way, like they do financial records. With the advent of EHRs, and the personal health record component that is part of the EHR vision, consumers will suddenly have easy access to a great deal of their medical history. I think they will need help in understanding that information and in using it in ways that enable them to become true partners in managing their health care.

Patty: I'm sure you are right. To comply with the income tax laws, most people maintain some orderly records related to their finances just in case the Internal Revenue Service audits their tax returns. Some people maintain records of their medical expenses, especially if they are itemizing their deductions when they fill out their tax forms. However, I suspect that keeping copies of the clinical records is rare, or hit and miss at best.

Leslie: I know that I have been getting more clinical information in writing from my various providers in recent years. It isn't unusual for me to ask my doctor to fax the results of my lab work to me. (He doesn't have an EHR yet.) As far as organizing the documents I receive, I simply put them into one file folder in my home office marked medical record. It doesn't represent a complete medical history by any means. And I would never think to bring it with me if I were visiting a new physician. I would still ask my old providers to send copies of my records to my new doctor.

Patty: However, as pointed out in the HL7 white paper, the new role of consumers and their medical records is more than simply storing and accessing medical information. The goal is for patients to become full partners with providers in managing their health. In the past, patients were not expected to make notes or

record information in their own medical records. That was always the clinician's territory. But clearly we are seeing that practice change. For example, managing chronic diseases such as heart disease or diabetes is a natural segue to patient self-monitoring and reporting. Enabling providers and patients to document and communicate through an EHR system should prove more efficient for providers and more convenient for consumers.

Leslie: The exploding use of the Internet by consumers seeking information about health-related topics is already leading to greater health literacy in our society. As we agreed earlier, health literacy must be a priority in a consumer-driven health care system. If the concept of MSAs really takes hold and consumers start making more direct decisions about how to allocate their resources for health care, they will need to be able to make informed choices.

Patty: That's right; we don't want people skipping preventive care to save money. All citizens will need to be educated about health issues. I'm starting to think that our profession's former title of medical record librarian may need to be reprised. One aspect of the consumer advocate role may be that of medical reference librarian, helping people find reliable, current information on health topics relevant to their personal situations.

Leslie: As I think about these various aspects of the consumer health information advocate role: privacy and release of information advisor, information management teacher and reference librarian, I see an expanding HIM body of knowledge and so many new opportunities for our profession to contribute to the health of our communities and our nation.

Patty: It sounds like HIM professionals need to be developing formal action plans for consumer health information advocacy in their own organizations. In our competitive health care industry, it will be a clear advantage for their organizations to be perceived in their communities as the best resource for guidance about the consumer's own health information, as well as general knowledge of health and the health care system.

Leslie: It is an opportunity for HIM to lead another new multi-disciplinary initiative. Tying it to the evolving EHR and e-HIM can help ensure that others in the organization view the initiative as an important aspect of the emerging e-HIM profession. But once again, we must be proactive. I suspect others may want to compete with us for this role. Nurses do a lot of patient education. Medical librarians will logically see the role of reference librarian as theirs. It is a collaborative endeavor to be sure, but one that I think HIM professionals can and should lead with distinction.

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