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Carle Goes HITECH: Ethical Challenges Related to MyCarle Online Records

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INTRODUCTION

In February 2009, President Barack Obama authorized the American Recovery and Reinvestment Act, frequently referred to as the “Stimulus Plan.” Part of that legislation includes the Health Information Technology for Economic and Clinical Health Act, or HITECH.1 As its name implies, a significant portion of the funds allocated through HITECH are devoted to incentivizing healthcare institutions to become “meaningful users” of electronic health records (EMR). The drive to increase the use of EMR is aimed toward lowering healthcare costs while increasing the quality of care through improved care coordination, accuracy of diagnoses and health outcomes, and increased patient participation in their own care.2

Although it will take time to find out if HITECH leads to those desired outcomes, healthcare providers and institutions are nonetheless faced with numerous challenges associated with implementing such large structural changes. Many of those challenges are practical in nature, as Carle’s Information Technology (IT), Administration and EPIC EMR teams can surely attest, creating questions such as:

- What is the technological infrastructure that is necessary to support EMR?
- How can physicians and care providers be trained to transition from paper-based records to EMR?
- How can a high level of patient care be maintained during the transition period? How much will it cost?

Accordingly, healthcare institutions’ time and resources have been largely devoted to such larger structural issues.

THE HITECH ACT

Most scholarly analysis of the HITECH Act has focused on those practical implementation concerns or on HITECH’s relationship to the 1996 Health Insurance Portability and Accountability Act (HIPAA).3-5 Yet the challenges posed by HITECH are not limited to those issues—HITECH also presents healthcare providers with significant ethical challenges. To understand what those challenges are, it is necessary to examine specific provisions of HITECH. For example, the Centers for Medicare and Medicaid Services (CMS) have established 14 objectives and corresponding measures by which healthcare entities will be judged as “meaningful users” of EMR who are eligible for HITECH’s financial incentives. One of those objectives is to “provide patients with an electronic copy of their health information (including diagnostic test results, problem list, medication lists, medication allergies, discharge summary, procedures) upon request” within 3 (three) business days.6 In response to this task, Carle has recently rolled out “MyCarle Online Records,” a securely encrypted, password-protected online portal that provides patients with access to those portions of their EMR.7 With MyCarle, patients now have near-immediate access to an enormous amount of information about their health, right at their fingertips.

Research indicates that 78% of Americans use the Internet, 61% of Americans turn to the Internet for medical information and up to 70 million Americans have some form of electronic access to their personal medical records.8 With the increasing popularity of the Internet, it is understandable why legislators would be interested in developing ways to integrate web-based technologies into the healthcare setting.
However, the HITECH requirements fail to address the “digital divide,” the discrepancies between those people who have Internet access and those who do not. In the healthcare setting, this is especially problematic because those groups who are least likely to have Internet access (racial/ethnic minorities, the elderly and the poor) tend to be the groups who are most likely to be affected by poor health issues. For example, in late 2009, Yamin et al conducted a survey of over 75,000 patients within a northeastern US health system and found that Hispanics were less likely to take advantage of access to their EMR compared with whites, and those individuals with lower incomes were less likely to use web-based technologies than their wealthier peers. In other words, the populations who would most benefit from learning more about their healthcare are those who are also least likely to have access to that very information.

To further complicate matters, research indicates that the groups who have the most to gain from learning more about their healthcare are also among the populations who are likely to have the lowest rates of health literacy. Health literacy, which is “the degree to which individuals can obtain, process, and understand the basic health information and services they need to make appropriate health decisions,” refers to a person’s ability to interpret medical documents (such as medication instructions or a consent form), understand quantitative data (such as lab results), and ask appropriate questions. Although limited health literacy is a widespread problem in the US, the elderly, racial/ethnic minorities, and the poor are disproportionately affected by low rates of health literacy. Thus, the individuals who have the most to gain from increased access to their medical information tend to be those who are least likely to be able to understand that information. Even if the electronic records promoted by HITECH were to overcome the chasm of the digital divide, there still exists a significant gap between access and understanding that no HITECH incentive program can overcome.

**CONCLUSION**

So where do Carle healthcare providers find themselves in this situation? Like the majority of other healthcare institutions, we are faced with a substantial financial incentive—so significant that HITECH compliance is essentially a requirement—to provide patients with electronic access to their medical records in a timely fashion. To see lower healthcare costs, improved outcomes, and increased patient participation, MyCarle is not enough. **Care providers must be prepared to tolerantly work with their patients as they learn how to use this new tool in a helpful manner.** Although most of us never trained to be IT professionals, information technology is now an inescapable aspect of our professions. Care providers must also be able to take the necessary time to speak with patients and not merely refer them to MyCarle for more information. Again, access does not equal understanding. Understanding must be assessed through direct interaction with a patient and through time-intensive conversations to ensure that patients have a level of health literacy adequate enough to effectively utilize the MyCarle system for their benefit.
REFERENCES


