Privacy: Protection or Obstacle?

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By Diann H. Smith, MS, RHIA, CHP, FAHIMA

As health information management (HIM) professionals, we are privileged to be members of a profession that advocates for healthcare consumers. As a mother, caregiver, and HIM professional, I am often challenged with current processes in place for patients and their caregivers to obtain health information. As HIM professionals, we are vital in developing standards that protect our patients, and we have a duty to protect them daily. As healthcare has evolved with electronic health records (EHRs) and increased processes to protect our patient's data, have we created barriers for the ones we are trying to protect?

Take a moment and view this from a consumer, caregiver, and patient perspective. For five years while my daughter was receiving treatment for cancer, she would encounter multiple providers with EHRs and would be required to sign an authorization for me as her caregiver to have retrospective access to her health information. Her desire was to provide me ongoing access to her health information on all future visits. She would have conversations with various HIM departments and providers stating her wishes, and with each conversation or provider encounter she had to sign an authorization to release her protected health information (PHI). She was clear in her expectations and desires for her caregiver to have the same access as she did. However, at the next encounter she'd become frustrated because again she'd be required to sign an authorization form, which simply did not make sense to her and was an additional inconvenience.

As her cancer progressed, she moved from specialist to specialist—and would have to obtain her records to make them available to the next provider, because of the lack of interoperability between EHRs. One might say this is additional unwarranted stress in an already stressful time.

It was a dance. The system, in which HIM plays a part, has put these barriers in place. As an HIM professional I am knowledgeable on how to navigate the system, but our consumers typically do not have the same knowledge base. My family's story is not unusual—many patients have caregivers who need access to their health information as they help navigate the complexities of care.

In the age of instant access to unlimited information, consumers expect real-time availability to their records and often need to designate the same rights to their caregivers who are co-managing their care. Patient portals provide real-time access and are being rolled out nationally. Access for the caregiver as illustrated above is retrospective and cumbersome to navigate. Privacy is important, but access to health information that allows timely clinical care is also important—and it's the law!

As technologies emerge, we must focus on standards and interoperability to support patient access, proxy access, and exchange between organizations. We also have a responsibility to work within our organizations to make information easily accessible for our patients by developing practices that support interoperability and the patient "owning" the right to designate a personal representative to access their PHI and disclose it to appropriate parties as the patient wishes.

Protecting the privacy and security of the health record is important, but are we really meeting our patients' needs with current organizational processes? I encourage each of us to focus on educating our patients, creating standards, and advocating for interoperability.

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