Building Trust into the NHIN: Key Legislation Can Ensure the Privacy of Personal Health Information

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by Dan Rode, FHFMA

We have seen considerable progress this year to spearhead IT implementation in healthcare organizations, with the goals of a standard electronic health record and a national health information network in the coming years. Many believe these developments will improve the quality, effectiveness, and efficiency of our health system.

The US federal government and healthcare industry are finalizing the road map. The HIM profession is gearing up to join the transformation. Consumers are preparing to exchange information by developing their personal health records. But do consumers trust the healthcare system? With reports of identity theft and lost or stolen records in the news, do people believe their health information is private and secure?

Health information managers have labored extensively to comply with the HIPAA privacy rule, but the public must also be ready to allow the electronic transfer of their healthcare data. Our professional efforts are geared to the success of the new electronic era, but as Health and Human Services Secretary Michael Leavitt has noted, if we do not build trust into the health IT system, it will fail.

Exchanging Data: A Good Thing

If an individual's healthcare information stayed with only one primary provider, privacy or confidentiality would probably not be an issue. But individuals are unlikely to have only one healthcare provider. Healthcare information must be stored and exchanged with ancillaries, specialties, pharmacies, emergency medicine, and other services that are outside of primary physicians or clinics. Formal and informal statistics show that the public recognizes the need for information to be shared among this collection of providers, and if given the choice between halting the exchange of their health information or receiving necessary services, they choose that the data be exchanged to receive proper care.

Providers also exchange patient data with health plans, insurers, and payers. Most providers offer patients the chance to stop the exchange of information to third-party payers, but given the choice of paying the bill and having it paid by the third party, the individual usually opts to have the claim forwarded. Data is also exchanged for public health and other governmental reasons. In these instances, a law has been passed taking the individual's choice away for the common good of the community. However there is an additional degree of confidentiality imposed for certain cases.

Preventing Discrimination

No individual should fear that his or her health information could be used inappropriately against him or her. Most adults will stop allowing their healthcare data to be shared when they believe the information could be used in such a way that they or a family member could be discriminated against—usually by an employer or insurer. This can cause considerable anguish, especially if they have to bear the cost of medical services out of pocket.

Laws have been passed to protect individuals' confidentiality when a diagnosis is related to specific diseases such as drug or alcohol abuse, AIDS, and behavioral health. However, even in these cases it has been acknowledged that discrimination has occurred when errors resulted in the data being leaked.

The Genetics Case

While the science of genetics offers great hope, it also offers the potential risk of discrimination. With the mapping of the human genome, we now have the potential to know, through an individual's genetic makeup, what pre-existing conditions might eventually cause the individual or a member of the individual's family to succumb to a disease that in turn will result in a debilitating condition or the need to seek expensive medical services.

The key word here is potential. It is too early for science to provide a crystal ball with any measure of acceptable potential outcomes. But for some, even a small potential and seemingly negative future event are enough to cause a negative reaction, such as job or insurance discrimination.

For several years, members of the US Senate have passed legislation outlawing discrimination against individuals on the basis of their genetic information. This March the Senate passed the Genetic Information Nondiscrimination Act of 2005 (S. 306) unanimously. Unfortunately, the actions of the Senate have not transferred to the US House of Representatives.

In the House, representatives such as Louise Slaughter (D-NY) have struggled for years to build a majority for such legislation, only to see the leadership refuse to have a vote taken. In its efforts to secure such legislation, AHIMA has often met employers and insurers actively working to defeat the bill. It's no wonder, then, that individuals fail to take some genetic tests for fear that the results may be leaked. No wonder, too, that stories of such information causing negative coverage decisions and job discrimination have caused the public to distrust today's healthcare information system, let alone any future health information network.

As healthcare professionals we know that use of an individual's health information can potentially lead to some form of discrimination or cause perceived negative consequences. Add to this the frequent news of lost or stolen private information in the health, banking, and financial sectors, and it is easy to see that building trust in a national health information network could become especially troublesome.

Passing Key Legislation

For many years AHIMA has supported genetic nondiscrimination legislation and has urged members to support such legislation in the form of letters, via our online Advocacy Assistant, to members of Congress. This summer AHIMA issued a position statement urging the US House of Representatives and the president to pass and sign legislation in 2005 to prohibit discrimination based on genetic information. AHIMA members are once again urged to support this legislation with members of Congress and in their community.

While nondiscrimination legislation is important, it is not the only action that must be taken to ensure that individuals can trust the healthcare system and allow their health information to flow within the healthcare system. Additional legislation is needed to expand such protection beyond just the misuse of genetic information; individuals can also be discriminated against on the basis of physical or medical health, even in cases where testing can be done to rule out such diagnoses.

Passage of a genetic nondiscrimination law is just the first step. Penalizing those who do discriminate on the basis of such information is also needed for the public to believe that the healthcare industry and the government are serious about the misuse of personal health information. Protections such as those highlighted in the genetic nondiscrimination legislation also need to be applied to all personal health information, and the prosecution of those who intentionally violate the law should also accompany such laws.

Over the last few years the Privacy and Confidentiality Subcommittee of the National Committee on Vital and Health Statistics has held a series of hearings on the misuse of health information. AHIMA's HIPAA compliance surveys have also highlighted the concern for situations not covered by HIPAA. We have our work cut out for us to ensure the confidentiality of health information, no matter where it is kept or sent, and to make sure that such laws apply to individuals and organizations that intentionally misuse health information for discriminatory practices or identity theft, no matter who they are.

HIM professionals are in a unique position to work with communities and patients to understand the need for and use of personal health information in the healthcare systems. As we build new electronic record systems and exchanges, HIM professionals can ensure that steps are taken to secure the confidentiality and security of health information. Applying our professional knowledge along with supporting legislation such as the genetic nondiscrimination act, we can build the trust to ensure our patients trust in our health information systems of tomorrow. Join your association in these efforts.

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