Securing Genetic Information: a New Challenge for HIM Professionals

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by Amber Trivedi

The call for legislation prohibiting genetic discrimination is growing, and for HIM professionals this requires the complicated task of securing genetic information. While the industry has extensive experience keeping medical records confidential, the difficulty of defining genetic information poses some new challenges.

A Matter of Privacy

Genetic privacy and the threat of discrimination have become major issues as genetic testing has become more commonplace.[1] Genetic counselors must be able to assure patients that their genetic information is stored securely and their privacy is protected. However, this becomes difficult with the integration of genetics and medicine, when the boundaries between genetic and nongenetic information begin to blur. Although medicine appears to be slowly moving away from genetic exceptionalism—the concept that genetic information is different from other health information—today's HIM professionals must deal with the public's current concerns.[2]

Regardless of their familiarity with genetic science, many people feel their individual genetic code is synonymous with identity and is therefore personal and private information—an idea that's been perpetuated by the media. Science fiction books and movies, such as the 1997 film *Gattaca*, suggest that human potential is determined by genetic makeup. Newspapers and magazines tout a gene's responsibility for medical or social dispositions such as the breast cancer gene, the Alzheimer gene, or the gay gene. With the misconception that genetic code alone determines fate comes the idea that this information can be used against us.

Fear of discrimination has become widespread among the public and has affected the impact of genetic medicine. According to a 2004 survey by the Genetics and Public Policy Center, 92 percent of those surveyed did not think employers should have access to genetic information, and 80 percent thought that insurers should not have access. These numbers represent an increase from a 2002 survey, when 85 percent and 68 percent felt access should be restricted for employers and insurers, respectively.[3]

When offered genetic tests, patients routinely ask about the risk of genetic discrimination. Frequently, someone—a family member, a friend, or even their physician—has warned them against genetic testing in order to avoid the risk of discrimination. As a result, patients are declining genetic tests or paying for tests out of pocket in order to circumvent this issue.

Separating Fact from Fiction

In reality, discrimination is not applicable to all genetic tests, and it is not the rampant problem it is perceived to be. The first step in alleviating concerns about genetic discrimination is to educate the public about the types of genetic testing available and their relation to current antidiscrimination laws.

Genetic testing is available for diagnostic and predictive purposes. Diagnostic testing applies to individuals who have an active disease, for whom genetic testing may provide a diagnosis. Predictive testing applies to individuals who do not have an active disease, but for whom testing may indicate a high risk of developing a disease in the future. Individuals who undergo diagnostic testing, and therefore have symptomatic disease, are protected from discrimination under the federal Americans with Disabilities Act. Therefore, discrimination only becomes an issue for those seeking predictive testing.

Despite the media hype, there have been few documented cases of genetic discrimination in the US. Nevertheless, the fear of discrimination has prompted legislative protection. Under HIPAA, genetic information is included in the category of protected health information, and genetic status cannot be considered a pre-existing condition in the absence of symptomatic disease. HIPAA also prohibits health plans from using genetic information to deny coverage or increase premiums.

Although HIPAA affords significant protection, many feel it is insufficient since it does not cover those outside of group plans (such as the self-insured). HIPAA does not address genetic information that is collected for research, and it does not prevent insurers from requiring genetic tests or disclosure of genetic information. Therefore most states have additional laws that prevent health insurance companies or employers from requesting genetic test results, though the level of protection varies greatly from state to state.[4,5]

Additional Legislation and What It Means

Regardless of HIPAA and the lack of documented discrimination cases, patients are still concerned about genetic discrimination because of anecdotal stories. These stories suggest that discrimination occurs despite current legislation, even though it is difficult to determine what is truth and what is urban legend. Additionally, patients fear that current laws do not address the possibility that insurers may disguise genetic discrimination as routine underwriting based on nongenetic data. Since it is difficult to prove genetic discrimination within the framework of HIPAA and current state laws, there is a growing public desire for genetic-specific legislation.

To address the need for additional protection on a federal level, lawmakers introduced the Genetic Information Nondiscrimination Act of 2005 (S. 306/HR 1227). It provides protections similar to HIPAA but specifically addresses genetic information. Additionally, it prevents health insurers from requesting genetic test results except as necessary for treatment, payment, or healthcare operations. This bill has passed the Senate twice but has not yet been put forward for a vote in the House of Representatives.

The argument against this legislation is that it is not necessary considering the lack of documented cases of discrimination and the fact that genetic information is included under HIPAA. Further complicating the matter, some feel that genetic-specific antidiscrimination laws have serious flaws since genetic information by definition includes family history. By including family history information, traditional underwriting practices would be considered illegal; and by not including family history information, genetic discrimination would be possible based on family history.[6]

The difficulty in defining genetic information raises the issue of genetic exceptionalism. Should genetic information be treated differently than other health information? Some feel that genetic information is akin to other categories of medicine that have special protections, such as mental illness or HIV status. In the age of electronic health records, some institutions have placed extra security (such as restricting access or tracking access) on these types of records. For example, records regarding a patient’s mental illness should be accessible only to a hospital’s psychiatric department. Another example is tracking access to HIV results. Access to these results is tracked to ensure that it is viewed only by those with authority to do so. Additionally, warnings about tracked access may be embedded into the HIV result text in order to act as a deterrent against access misuse.

Although the issues surrounding genetic information do not perfectly match these examples, these security techniques provide a template for HIM professionals to work with when establishing privacy measures for genetic records.

Implications for HIM Professionals

If an institution decides to secure (or store) genetic information differently than other health information, its challenge becomes defining what information is genetic and what is nongenetic. Separating these two categories is probably the main obstacle for HIM professionals, since genetic information is ubiquitous.

One example is a woman who elects genetic testing for mutations in the BRCA1 or BRCA2 gene (the breast cancer gene). If she tests positive, she is expected to have up to 87 percent chance of developing breast cancer and up to 54 percent chance of developing ovarian cancer in her lifetime. In order to reduce her risk, she has the option of getting more frequent screening (involving radiology, gynecology, or sonology), taking medications to reduce her risks (possibly involving medical oncology or gynecology), or undergoing surgery to remove her breasts or ovaries (involving surgical oncology or gynecologic oncology).

It may be easy enough to secure her records regarding her original genetic risk assessment and test result. However, each specialist she consults regarding cancer prevention must take into account her genetic status and document it to justify treatment recommendations. This makes securing her genetic information extremely difficult.

Because genetics is becoming an integral part of all fields of medicine, the genetics and medical communities are starting to move away from genetic exceptionalism. We now know that most conditions involve a genetic and environmental component. Genetics is no longer limited to rare diseases, and it will likely become just another piece of information in a patient's medical record. Nevertheless, the current social climate still harbors a strong fear of genetic discrimination, and the public will not embrace genetic technology until it feels it can do so without excessive risks.

Many patients are already sensitized from being discriminated against by insurers for reasons unrelated to genetics; and these patients may turn down genetic tests. Patients familiar with HIPAA expect the medical community to take added security measures to protect their genetic information. Until genetic exceptionalism ceases, and the public becomes aware of it, HIM professionals must keep abreast of genetic legislation and develop institutional standards for placing added security on this information.

Notes

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