From DNA to Data Privacy

Save to myBoK

by Barbara P. Fuller, JD, RHIA, and Jane Jeffries

Genetic research is revolutionizing healthcare by predicting diseases and revealing cures. At the same time, the information presents new challenges to HIM professionals charged with keeping this vital data from the wrong hands. Here's a look at the role genetic information is playing in healthcare and what you need to know about keeping it private.

From "designer" babies to predicting disease, genetic research is making headlines almost every day. What is it, what are the consequences, and what are the ethical implications for HIM? This article takes a look at the progress genetic research has made, as well as the roles state and federal legislation play in protecting it.

From Genes to Medicine

Let's start with the basics of life. One piece of DNA contains many genes, which in turn contain the basic information a body needs to function. The "letters" of the genetic code are nucleotides-adenine, thymine, guanine, and cytosine-that combine to form three-letter "words" instructing a cell how to make a protein. Proteins perform various activities within the cell.[1] These words are also the directions that make children resemble their parents or inherit their propensity or resistance to certain health risks. A misspelled word on a gene signifies a genetic mutation, which may be the root of a genetic disease. The complete set of genetic instructions for a human being is the human genome. .[2]

Through genetic research, doctors have been able to determine the genetic component of a growing number of illnesses. Some of the most well-known discoveries are the genes for cystic fibrosis, Huntington disease, and some forms of breast cancer. Genetic research has also revealed the genes behind diseases whose manifestations may also depend on environmental factors such as diet, hygiene, and access to healthcare. Truly, medicine is reaping the rewards of technology.

The next step in genetic research is to finish sequencing the human genome and develop tools for understanding its instructions. Jointly launched by the Department of Energy and the National Institutes of Health in 1988 through funding from Congress, the Human Genome Project aims to map and characterize each human gene. .[3] In June 2000, the Human Genome Project public consortium announced that it had assembled a working draft of the sequence and plans to complete the sequencing by the end of 2003. In the meantime, the Human Genome Project's discoveries are made available to the public every day via the GenBank Web site, so researchers worldwide can take advantage of the new genetic information. .[4] In the past year, this resource has led to the discovery of the genes responsible for deafness, kidney disease, and some forms of cancer. .[5]

What Can Genes Say About You?

Unlike some scientific discoveries that inspire wonder but don't affect daily life, the results of genetic research can play a direct role in a healthcare consumer's well-being. With the ability to recognize the genes responsible for Parkinson's disease or Huntington disease already at hand, those at risk for these diseases, such as family members of those with the illness, can be tested for them. Should a test reveal the genes for a disease that has not yet manifested, such as a form of colon cancer, the patient can take advantage of increased diagnostic surveillance, possibly improving his or her quality of life or chances for survival. Genetic tests may also reveal that a person is only a "carrier" of a certain genetic mutation. In these cases, the disease will not manifest itself in that person but could be passed on to his or her offspring.

Despite these obvious benefits, genetic research and testing have ethical side effects. Genetic information can, in many ways, be differentiated from other health information because it is not a current or past picture of a person's health; it is a look into his or her health future. .[6] In the wrong hands, this information can have major ramifications. For example, in one child custody battle, the court ordered one parent to undergo genetic testing to determine if that parent had the gene for Huntington disease. If the parent tested positive, the other parent was prepared to argue that the parent with the Huntington gene would not be a fit parent and thus would be unable to care for the child-even though there were no symptoms of Huntington disease yet. .[7]

There are equally high stakes in the work world. Employers who gain access to their employees' genetic information may leap immediately to incorrect and damaging conclusions. An employer who discovers an employee's propensity for a disease-even if the potential manifestation is decades away-may anticipate his or her diminished ability to do a job or an increase in the company's health insurance costs. The result can be termination. Parents of children whose genes predict disease may suffer the same fate. .[8] In cases where a potential employer makes a job offer contingent on medical clearance, access to genetic information may deal the death blow. Further complicating these situations is the fact that genetic discrimination in the workplace can be very difficult to prove.

Insurers may also want to obtain genetic test results, even though these results may not accurately foretell the future manifestation of a disease. However, patients want to keep their genetic information from the eyes of health insurers: in a Time/CNN poll conducted in 2000, 75 percent of those polled indicated they would not want their health insurance company to have information about their genetic code. .[9] And while insurers call for the appropriate use of genetic information and the protection of the privacy of an individual's information, they also wish to use genetic information to determine possible risk factors in underwriting. .[10]

Necessary Protections

Many think genetic information is more personal and more likely to be used for stigmatization or discrimination than most other types of health information. Genetic information has a history of misuse from the early 1970s, when carriers of the gene for sickle cell anemia were denied insurance coverage or charged higher rates even though they were not at risk of developing the disease. Does genetic information deserve extra protection, such as that afforded mental health information? Dr. Francis Collins, director of the National Human Genome Research Institute, has referred to genetic information as part of the "tapestry of medical information" and noted that "it is often difficult to decide whether you are looking at something that is genetic or is not." .[11] Genetics professionals, citizen and industry groups, and policy makers generally agree that it is not reasonable to separate genetic information from other medical information. Therefore, to afford adequate privacy protection for genetic information, we must afford high standards for the protection of all health information.

Alcohol or substance abuse health information, as well as mental health information, enjoy special privacy protections, of which most HIM professionals are aware. Genetic information presents another challenge to HIM professionals: knowing and understanding the state laws that protect it so they can protect the patient. So far, 24 states have laws concerning genetic information and the workplace, while 37 states have laws concerning genetic information and health insurance. Some of these laws prohibit both genetic discrimination and access to genetic information. Let's take a look at some state antidiscrimination laws that have privacy components: .[12]

- Wisconsin: As early as 1991, Wisconsin enacted legislation that prohibited health insurers from requiring an individual to reveal whether or not a genetic test had been obtained, or, if a genetic test had been obtained, from revealing the results of the test (WI ST 631.89)
- Massachusetts: In August 2000, Massachusetts enacted legislation prohibiting employment and insurance discrimination on the basis of genetic information. This legislation has a component that requires written consent for the release of a person's genetic information, and significantly, this consent "shall be distinguished from written consent for the release of any other medical information" (HB 5416)
- Missouri: A 1998 law prohibits health insurers from requesting genetic information and from inquiring whether a person has taken or refused a genetic test. Insurers are also prohibited from inquiring about the results of a genetic test (MO ST: 375.1303)
- Maryland: In 1996, Maryland enacted legislation to prohibit health insurers from requesting or requiring the results of a genetic test for use in underwriting. The legislation also prohibits the release of the results of a genetic test without the prior written authorization of the individual (Art 48A-Insurance Code, Section 223.1)
- California: California's laws prohibit health insurers from seeking genetic information for any nontherapeutic purposes. HIM professionals should note that it also provides for civil penalties if any person negligently discloses results of a test for a genetic characteristic except pursuant to a written authorization that specifies the nature of the information authorized to be disclosed (Civil Code Section 56.17)

In addition to the state laws that have already been enacted, keep in mind that for the past few years, hundreds of genetic discrimination and privacy bills have been introduced in state legislatures. Some of these bills would have modified existing legislation and some would have created an entirely new area of legislation, but almost all of them have a privacy component that could directly affect the release of genetic information from the medical record. This high level of state legislative activity with regard to genetic discrimination and privacy is likely to continue.

In February 2000, President Clinton signed an executive order that prohibits federal departments and agencies from using genetic information in any hiring or promotion action. .[13] The executive order prohibits a department or agency from requesting or requiring genetic test results from applicants or current employees. Additionally, multiple bills introduced in the 106th Congress would have extended the protections for genetic information included in the president's executive order to the private sector. However, none of these bills became law.

What About HIPAA?

Some protection for genetic discrimination is legislated under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) umbrella. .[14] HIPAA prohibits excluding an individual from group coverage because of past or present problems, including genetic information. It specifically prohibits genetic information, in the absence of a diagnosis of a condition, from being considered a preexisting condition. The act also prohibits charging an individual a higher premium than others in a group, but does not guard against the use of genetic information as a reason for charging higher premiums.

While the initial HIPAA legislation did not address the collection of genetic information by insurers, it called for federal legislation to protect the privacy of individually identifiable health information, and in the absence of federal legislation, required the secretary of Health and Human Services to promulgate regulations. Although the recently published standards for privacy of individually identifiable health information do not specifically address genetic information as a separate category, they provide comprehensive protection for all individually identifiable health information, including genetic information. .[15]

Growing Responsibilities

What are the responsibilities of HIM professionals in safeguarding genetic information? There are three answers:

- be aware of state laws regarding the privacy of health information, including genetic information
- ensure that state laws are followed
- monitor the contents of each medical record so health information from the record is only released according to the prevailing law

In many instances, HIM professionals have the ability and responsibility to ensure that state laws prohibiting access to genetic information are followed. With blanket signed releases from patients, insurance companies frequently request any and all health information in a patient's medical record. But though insurers may use the same request for information form year after year, HIM professionals cannot assume the laws have remained the same. HIM professionals must know how genetic information laws have changed as well as the contents of the patient's record.

Unfortunately, it can be difficult to keep track of relevant laws because genetic antidiscrimination laws and their privacy components can be found not only in the health records sections of the statutes, but also in sections covering workplace laws, insurance laws, or even civil rights laws. Further, the laws can be very specific about the information that can be released with and without specific authorizations, and the information that cannot be released to certain entities.

Scientific exploration yields advances in healthcare, which are often manifested as additional responsibilities in the HIM arena. When genetic information is in question, HIM professionals must uphold the obligations of legislative awareness and vigilance about medical record contents. Privacy is a core value of this profession and when this value is challenged, HIM professionals can take advantage of the laws designed to protect it.

Notes

1. NHGRI Glossary of Genetic Terms. Available at www.nhgri.nih.gov/DIR/VIP/Glossary/.
2. Rodsjo, Susan. "Truth and Consequences." Healthcare Informatics 17, no. 10 (2000).

3. NHGRI. "Understanding Our Genetic Inheritance: The US Human Genome Project; The First Five Years: Fiscal Years 1991-1995." Available at www.nhgri.nih.gov/HGP/HGP_goals/5yrplan.html.
4. The GenBank Web site is www.ncbi.nlm.nih.gov/ Genbank/index.html.
5. Testimony of Francis S. Collins, Director, NHGRI. "Hearing on Genetic Information in the Workplace." July 20, 2000. Available at www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/francis_72000_test.htm.
6. Hudson, Kathy L. et al. "Genetic Discrimination and Health Insurance: An Urgent Need for Reform." Science 270, no. 5235 (1995): 391-393.
7. Rothstein, Mark R. "The Use of Genetic Information for Nonmedical Purposes." Journal of Law and Health 9, no. 1 (1994-1995).
8. "Genetic Discrimination and Health Insurance," 391-393.
9. Borenstein, Seth. "The Human Genome Project: Breakthrough to Aid Battle Against Almost All Diseases, May Cut Cancer Deaths to Zero." Detroit Free Press (June 27, 2000). Available at http://freep.com/news/nw/gene27_20000627.htm.
10. "Genetic Profiles Headed for CD-ROM." Best's Review September 1998 page 86.
11. Remarks of Francis S. Collins, Director, NHGRI, before the first meeting of the National Bioethics Advisory Commission, October 4, 1996.
12. For a comprehensive list of all state laws regarding genetic discrimination and privacy, go to www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/insure.htm and www.nhgri.nih.gov/Policy_and_public_affairs/Legislation/workplace.htm.
13. "Order Halts Genetic Bias." Journal of AHIMA 71, no. 4 (2000): 18.
14. Health Insurance Portability and Accountability Act, 104 Public Law No. 104-191, 701, 11-STAT, 1936 (1996).
15. 65 Fed. Reg. 82,381 (2000)(to be codified at 45CRR pt. 160 and 164 (proposed Dec. 28, 2000). Available at www.access.gpo.gov/su_docs/fedreg/a001228c.htm.

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- Billings, Paul R. et al. "Discrimination as a Consequence of Genetic Testing." American Journal of Human Genetics 50, no. 3 (1992): 476-482.
- Knoppers, B.M. et al. "Professional Disclosure of Familial Genetic Information." American Journal of Human Genetics 62, no. 2 (1998): 474-483.
- Medical Research Council. "Demystifying Genomics." Available at www.mrc.ac.uk/r_a_t_p1.html.
- Sobel, Richard, and Harold J. Bursztain. "Ban Genetic Discrimination." The Boston Globe (August 7, 2000).

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Read up on Genetic Information

- Want to know more about genetic information and related privacy and protection issues? Following are some helpful sources:
- Collins, Francis S. "Shattuck Lecture-Medical and Societal Consequences of the Human Genome Project." The New England Journal of Medicine 341, no. 1 (1999): 28-37.
- Fuller, Barbara P. et al. "Privacy in Genetics Research." Science 285, no. 5432 (1999): 1359-1360.
- Fuller, Barbara P. and Kathy Hudson. Genetic Information. In Ethical Challenges in the Management of Health Information, edited by Laurinda Harman. Gaithersburg, MD: Aspen Publishers.
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- Rothenberg, Karen et al. "Genetic Information and the Workplace: Legislative Approaches and Policy Challenges." Science 275, no. 5307 (1997): 1755-1757.
- Weiss, Rich. "Genetic Tests in Workplace Can Be Privacy Breach, Appeals Court Says." Washington Post (February 5, 1998).

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