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Genetic Privacy

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Advances in genetics have ignited a public debate over the privacy of genetic information and samples. The personal, predictive and familial nature of genetic information poses a new threat to civil liberties, according to some commentators. Others contend that genetic information is simply another type of health information and, therefore, should be treated similarly under the law. Regardless of whether genetic information is exceptional, genetic privacy remains linked to the larger policy issue of health information privacy. Therefore, an understanding of broad medical privacy protections and genetic-specific protections, both at the state and federal level, is necessary to develop informed public policy for genetic privacy.

Federal Action

In April 2001, the Department of Health and Human Services adopted "Standards for Privacy of Individually Identifiable Health Information," as required by the Health Insurance Portability and Accountability Act of 1996 (HIPAA). Health plans, health care providers, and other entities covered by HIPAA must comply with these standards—known as the HIPAA rules—by April 2003, or April 2004 for small health plans. HIPAA compels the health insurance industry to make changes intended to provide patients greater control over medical information. At the same time, the HIPAA rules seek to promote public health, and, therefore, allow some exceptions to the limits on disclosure for public health agencies.

State Action

Laws in every state protect the privacy of medical records to some degree. In addition, genetic-specific privacy protections exist in 28 states, although the measures vary widely. Washington became the first state to treat genetic information the same as other health data under privacy law when it amended its health privacy law in 2002 by adding genetic information to the definition of protected health information. All state genetic privacy laws, with the exception of Washington's, tend to include a few basic characteristics. First, these laws take a "genetic exceptionalism" approach, which means that they treat genetic information differently from other medical records. Second, genetic privacy protections often focus on the information rather than on the user or use. Third, state genetic privacy laws rely on various measures to safeguard genetic information during different handling processes—like testing, acquisition, retention and disclosure. Finally, genetic privacy laws are designed to promote greater individual control over personal genetic information but use different means—such as consent requirements, rights to access, civil remedies and property rights—to achieve this end.

Laws in 16 states require informed consent for either a third party or insurers to perform or require a genetic test or obtain genetic information, and 25 states require informed consent or written authorization for either a third party or insurers to disclose genetic information. Michigan, Nebraska and South Dakota place higher standards on genetic testing, but treat the information like other health data once it is created.

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State Genetic Privacy Laws		
Applies to	Any Party	Arizona, Delaware, Florida, Illinois, Massachusetts, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, South Dakota, Texas, Vermont
	Insurers	California, Colorado, Georgia, Hawaii, Louisiana (and state agencies), Maryland, Rhode Island (and employers), South Carolina, Utah (and employers), Virginia, Washington
	Others	Arkansas (researchers only), Michigan and Nebraska (physicians or individuals conducting a genetic test)
Informed Consent/Written Authorization Required To	Perform or Require Genetic Test	Arizona, Florida, Georgia, Massachusetts, Michigan, Nebraska, New Mexico, New York, South Carolina, South Dakota, Vermont
	Obtain Genetic Information	Delaware, Nevada, New Jersey, New Mexico, Oregon
	Retain Genetic Information	Delaware, Nevada, New Jersey, New Mexico, New York, Oregon
	Disclose Genetic Information	Arizona, Arkansas, California, Colorado, Delaware, Florida, Georgia, Hawaii, Illinois, Louisiana, Maryland, Massachusetts, Missouri, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, Rhode Island, South Carolina, Texas, Vermont, Virginia, Washington

Property Rights. Consumers of health care services and research institutions both have a stake in property rights to genetic information. The debate centers on two types of property rights—intellectual and personal. Intellectual property rights provide an incentive for researchers to recover costs by allowing discoverers of a gene and its function to apply for a gene patent through the United States Patent and Trademark Office. Patents have been awarded for numerous genes—including those associated with breast cancer—but many individuals are disconcerted by the notion that corporations may own rights to their biological material. Some observers contend that patents provide an incentive, but others believe that the fees linked to the use of patented genes will slow scientific progress.

While the federal government has focused on the patent system, some states have looked at personal property issues. Colorado, Florida, Georgia and Louisiana explicitly define genetic information as personal property based on the belief that individuals should be able to own this uniquely personal information. Some genetics researchers express concern that that these laws may permit study participants to interfere with research projects or to stake claims to profits derived in part from the study of their genes. In 2001, Oregon repealed a property right to genetic information and DNA samples that originally passed in 1995.

Balancing Privacy with Other Values. Privacy undeniably has great value, but policymakers also should recognize the effects of privacy laws on other social goods, such as health care, medical research and public health. Privacy protections frequently conflict with these values, for example, when laws require health care providers to obtain patient consent for each disclosure of genetic information, even if to consult with a colleague on a diagnosis or treatment. The future challenge for policymakers lies in striking an equitable balance among privacy protections and other worthy goals.

Selected References

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