Towards a Unified Approach on Protection of Genetic Information

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Genetic information is of great value in various forms of research and, as a result, is being used with increasing frequency and in a wide variety of different applications. However, the use of genetic information has raised concerns about the potential for misuse and abuse. Accordingly, there have been a number of laws and proposals for laws that would limit the use of genetic information. Generally, these laws have taken one of two approaches: it is either focused on categorizing genetic information as something that is private to the individual and therefore, cannot be disclosed without the individuals’ consent or it has focused on labeling genetic information as something that is proprietary to the individual and is thus not capable of being taken or used in the absence of the permission, and perhaps, even payment, to the individual owner. This article proposes to examine these two different approaches and how they are being implemented through legislation. In doing so, we expect to highlight the need for a more unified approach to addressing concerns about the use of genetic information.

Why Are There Special Concerns about Genetic Information?

While many individuals are concerned about protecting the privacy and controlling the use of their personal information, some people are of the view that genetic information warrants special protection. The perception that genetic information can serve as an important predictor of the health of not only a particular individual but also her family members has led to concerns that employers and insurers may use this information as a means for limiting such individuals’ employment opportunities and/or insurance coverage.1 While there continues to be debate about the actual existence of genetic discrimination, regardless of what data reveals about the extent of genetic discrimination, it is clear that information garnered through the use of genetic tests may be of potential interest to not only the particular individual who has been tested but also to other entities including employers, schools, insurers and medical researchers. Without adequate safeguards, genetic information could be misused and, even abused.

Approaches That Emphasize Privacy

Special Protection for Genetic Information?

In the United States it is well established that medical information is confidential. Laws in all states restrict access to medical records and new federal regulations enacted under the Health Insurance Portability and Accountability Act of 1996 (“HIPAA”) provide comprehensive protection to individually-identifiable health information. However, there is debate over whether genetic information should be protected, as another component of health data, or by special genetic privacy laws. Opponents of special protection for genetic information often contend that such information is really no different than other health data and, accordingly, special protections are not warranted. Opponents of genetic exceptionalism also argue that instead of focusing on special protection for genetic information, the protection afforded to all health information should be strengthened. On the other hand, advocates of enhanced protection for genetic information focus on the stability and unique predictive qualities of genetic information as evidence that such information deserves special consideration.

Legislation

While HIPAA does not focus on genetic information, it does provide some protection against genetic discrimination by requiring that genetic information may not be used to deny or limit health insurance coverage for members of a group plan. However, the law does not prohibit rating based on genetic information, nor does it prevent health insurers from disclosing or demanding access to genetic information.

At the state level, there is a considerable amount of often-conflicting legislation regarding genetic privacy. Currently, a number of state laws require informed consent for a third party either to perform or require a genetic test or to obtain genetic information. In addition, a number of states require written authorization to disclose genetic information. Furthermore, some states also mandate individual access to personal genetic information. The fact that states that have chosen to protect the privacy of genetic information have done so in such disparate ways offers further evidence that a more unified approach is necessary.

Advantages and Disadvantages of the Privacy Approach

In some ways, it appears useful to address individuals’ concerns by focusing on protecting the privacy of genetic information. After all, if employers, insurers, and other entities do not have access to individuals’ genetic information, they cannot use the information to discriminate. However, the privacy model does have its drawbacks. One of the main disadvantages of this approach is that it does not provide individuals with continuing control over the use of their information. For example, legislation that emphasizes privacy rights may require that an individual must provide consent before her genetic information can be disclosed to third parties. However, once consent is provided, in most cases, she will not be able to control how her information is being used by any

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2 Public Law 104-191.
3 See, e.g., Lawrence O. Gostin and James G. Hodge, Jr., Genetic Privacy and the Law: An End to Genetics Exceptionalism, 40 JURIMETRICS J. 21, 24 (1999).
subsequent entities that come in contact with it. Additionally, placing emphasis on the privacy of genetic information may create obstacles to the use of genetic information for positive purposes, such as the prevention and early detection of disease.

**Approaches That Emphasize Property Rights**

As an alternative approach of protecting an individual’s genetic information, some jurisdictions, in lieu of privacy legislation, recognize a protectable property interest in an individual’s own genetic material. By receiving a property interest an individual may be given a more robust bundle of rights and protections than through privacy legislation alone. It has been observed that a privacy right merely affords an individual a “right of non-interference” while a property right is a “right of positive entitlement.” Thus, through property rights an individual could have a series of rights regarding the control, possession and transferability of genetic information that are unavailable through privacy legislation.

Even though genetic information possesses certain property-like traits, without legislation recognizing genetic material as personal property, the decision as to whether genetic information is afforded the same rights and protections as personal property under the common law will be left to the courts. When confronted with this very issue the Supreme Court of California held that an individual does not retain a protectable property interest in his excised cells. In *Moore*, plaintiff’s spleen was removed and, without plaintiff’s permission, used for medical research. Plaintiff brought suit against his doctors for *inter alia* conversion of his genetic material. After balancing the relevant public policy considerations, including the impact on the research community, the Court was unwilling to expand conversion law to cover genetic material.

**Legislation**

Some states have chosen to recognize an individual’s property right in his genetic information. In Florida, for example, “the results of DNA analysis, whether held by a public or private entity, are the exclusive property of the person tested.” Similarly, Colorado has taken an approach that emphasizes the proprietary nature of genetic information, providing that, “[g]enetic information is the unique property of the individual to whom the information pertains.” In each of these states, however, an individual’s ownership right in his genetic information is not absolute and certain exceptions are recognized.

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6 Dr. Graham Laurie, *Privacy, Property or Permission? Need Our Models for Regulating Personal Genetic Material be Mutually Exclusive?*, Proceedings of the Third International Conference Law and Technology at 16 (Nov. 6-7, 2002).

7 See *Moore v. The Regents of the Univ. of California*, 51 Cal. 3d 120 (1990).

8 Id. at 147.


Advantages and Disadvantages of the Property Approach

Proponents of the property approach argue that “[t]he added value of a property model lies in its ability to empower individuals and communities and to provide the crucial continuing control over samples or information through which on-going moral and legal influence may be exerted.” 11 Additionally, greater control over the use of samples might encourage otherwise reluctant individuals to participate in research projects. Apart from the control aspects, others favor the property model because it could allow research participants to share in the profits achieved through use of their genetic material.

On the other hand, opponents of the property approach see it as a great impediment to scientific research. They believe that scientists might be dissuaded from conducting important research if they are required to trace the chain of title of each sample used or face potential liability. Moreover, others fear that the recognition of personal property rights could lead to the exploitation of donors.

Conclusion

While genetic information holds great promise for society at large, as been demonstrated herein, the challenge of determining the proper balance between privacy concerns and fair use of genetic information has not yet been resolved. If left unresolved, going forward, the absence of a uniform legal approach for balancing individuals’ privacy and proprietary interests in genetic information may create obstacles to the further development and advancement of genetic research.

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11 Laurie, supra note 7, at 19.