Background on Genetic Discrimination

When a railway worker filed a workers compensation claim, he was asked for a blood sample. Unbeknownst to him, the blood was sent to Athena Diagnostics to be secretly screened for a gene thought to predispose people to carpal tunnel syndrome. The ultimate goal of such screening would be to provide companies with a defense: that they have no obligation to compensate workers for carpal tunnel injuries because the workers' genes, not the job, caused the problem. The worker filed suit against the railway in Iowa claiming the company invaded his privacy by peeking at his genes.[1]

Defining what constitutes "genetic testing" or genetic information is difficult because while many common ailments, such as diabetes and asthma, are known to have a genetic component, routine tests designed to detect the symptoms of the disease are not considered true "genetic tests" because they do not attempt to identify the gene mutation causing the disorder. Asking someone if their family members have a history of Huntington's disease or diabetes is not a predispositional "genetic" test. However, answers to questions of family medical history are in themselves genetic information because the answers may reveal the presence of an inherited disorder in the family. Even if there were no specific genetic tests being performed, genetic information about employees can be gained by routine medical examinations and family histories.

Genetic information is sometimes called "predictive," but a better term is "predispositional" because genetic information does not actually predict that someone will have a disease, but instead shows that someone has a higher chance than the average person of exhibiting the symptoms of a disease or disorder. For example, as a group, women with the 185delAG genetic mutation have a statistically higher chance of having breast cancer. But half of the women with the mutation will *not* get breast cancer; each woman with the mutation has a 50% chance she will *not* get breast cancer. In this sense, the "predictive" test for the 185delAG genetic mutation does not predict that a woman *will* get breast cancer later in life, because the test only indicates that the woman with the mutation is generally more likely to get breast cancer than someone without the genetic mutation. And the vast majority of women who develop breast cancer (85 to 90%) do *not* have an inherited genetic susceptibility to the disease.

Increasingly, healthy people are tested for diseases that may not manifest, if at all, until later in life, a practice that is creating a new class of individuals referred to as the "asymptomatic ill." An individual may want to learn about his or her genetic makeup *before* disease symptoms manifest so that he or she can predict (and possibly avoid or limit) future diseases. Others may want to use the information as well; an employer may want to test its employees for a mutation that, if present, makes them more likely to suffer harmful effects from workplace toxins. Even if well-intentioned, the employer may limit the job opportunities of healthy employees with the mutation by reassigning them to lessen their exposure to the toxins.

Many institutions, including insurers, employers, or schools, have incentives to discriminate between people based on their genetic makeup. Employers and insurers could decide to reject healthy applicants just because their genes may indicate that they (or a child or spouse) have a statistically higher chance of needing expensive health care in the future. When faced with applicants having similar grades and experience, schools could simply choose to admit those whose genes suggest they are smarter or have a statistically higher chance of avoiding a genetic disorder and having successful careers.

Concerns about institutional access to and use of genetic information impacts individuals' health care and scientific research in general. Prominent genetics researcher and director of the Human Genome Project Francis Collins warns that genetic research on certain cancers has been slowed because people have been deterred from participating in genetics research, fearing genetic discrimination. Genetic information has also been used as a basis for genocide in some countries and, in this country, was used as a basis for involuntary sterilization of thousands of people thought to be "genetically unfit." So as the volume of genetic information grows, it is important for individuals and society to decide not only who should be allowed access to genetic information, but how that information may be used.

Instances of genetic discrimination, like other forms of discrimination, are difficult to identify and measure. Institutions might not say whether they are performing genetic testing or engaging in genetic discrimination. Individuals who feel victimized by genetic discrimination may not admit to it for fear that the information will be used against them by others. Third parties, such as genetic counselors or health providers, who are asked about incidences of genetic discrimination may not know whether a patient who received genetic testing or counseling was later subject to any adverse decisions because of the information or services the patient received. There is also some confusion among the public and even researchers who study genetic discrimination as to what types of information constitute 'genetic' information. For example, in one of the earliest studies about employers who were gathering genetic information, many employers who were reporting that they did collect or require genetic information were, in fact, only conducting blood or urine testing, and not actually testing the biologic samples to identify genes or gene products.[2] In another study, the researchers themselves did not consider the collection of family history data to be "genetic" information for discrimination purposes, despite the fact that history about familial, inherited disorders clearly could be used to make assumptions about whether an insurance or job applicant has a higher probability of exhibiting those inherited disorders in the future.

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[1] Tamar Lewin, "Commission Sues Railroad to End Genetic Testing in Work Injury Cases," N.Y. Times, February 10, 2001; Sarah Schafer, "EEOC Sues to Halt Worker Gene Tests," Washington Post, February 10, 2001.

[2] *See* Am. Mgmt. Ass'n, 1998 AMA Survey: *Workplace Testing and Monitoring* 5.