

The Ethics of Genetic Screening

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Introduction

The development of the Human Genome Project has raised many privacy concerns regarding the use of genetic screening in employment, health premium coverage, and data-mining. Moreover, what causes extreme concern is the lack of direct government regulation addressing the use of such information. There is no law directly addressing this issue or who should be given access to this information. This paper will discuss how the information found from genetic screening limits the rights of individuals in employment and insurance considerations while increasing the accessibility of medical data to third parties. Undoubtedly, there is a need for more government regulation to prohibit the misuse of genetic data as well as a need for companies to abide by ethical standards to ensure the sound applications of this information.

Origins of Genetic Screening

The Human Genome Project (HGP), formally started in 1990, is a 13 year effort coordinated by the federal government. The goal of this project includes developing an information system for collecting, storing, retrieving, analyzing, interpreting, and distributing the large amounts of data generated by the research. Also, HGP is a research effort to determine the sequence of the three billion chemical base pairs that make up the human DNA and to identify the approximately 35,000 genes in human DNA.¹ Currently, the project results have led to the identification and availability of three types of genetic information that can ultimately be used for healthcare-related decisions. The three types of genetic screenings involve: the presence of diseases (e.g., Cystic fibrosis or Huntington's disease), genetic risk for diseases (e.g., breast cancer or male pattern baldness), and characteristic traits (color of eyes or height).²

The successful completion of mapping and sequencing of the human genome in 2003 has resulted in an extensive amount of information from voluntary participants.

This process has allowed the genetic information of countless individuals to be analyzed and stored electronically. Improper uses of such information could have led to severe and negative impacts on society. The Ethical, Legal, and Social Implications (ESLI) Research Program, created in 1990, is part of the Human Genome Project, and more specifically, the National Human Genome Research Institute. According to Genome.gov,³ the program “funds and manages studies” to “foster basic and applied research on the ethical, legal, and social implications of genetic and genomic research.” As the first bioethics program to take a proactive approach to handling such ethical issues, it aimed to stimulate public discussion of these issues as well as to develop ways to ensure that uses of genomic research would benefit society.⁴

Application of Genetic Screening

To date, genetic information is used in several ways. The Environmental Genome Project (EGP) seeks to “improve understanding of human genetic susceptibility to environmental exposures, which includes the goal of understanding how individuals differ in their susceptibility to environmental agents and how these susceptibilities change over time.”⁵ The EGP is part of a larger initiative involving genetic and genomic research on population genomics. It uses gathered public medical records of diseases and genetic information for research in specific population related diseases. The goal of EGP is to identify specific genes responsible for common chronic diseases in large populations. For example, the project could help identify populations that have a high percentage of breast cancer and heart disease.⁴ Having this information could then help the pharmaceutical and medical research facilities to increase resource capabilities.

Additionally, faster methods of testing DNA samples are being developed to accelerate genomic research. The use of faster computers and advanced software are used to compare and contrast DNA variations as well. Because of advances in information and communications technology and genomic technologies, it’s easier to identify groups of individuals and groups that are susceptible to certain kinds of diseases. This sort of information is crucial for society’s benefits in medical and genetic advancement because it will help pharmaceutical and research companies to

better treat and study this population.¹ But as a consequence of genetic testing fears, research subjects are less willing to volunteer their genetic information than before.

Genetic information is also used in the context of criminal prosecutions, population genomics, genetic screening for diseases and specific traits, DNA evidence of murder and rape cases, and paternity litigations, just to name a few. Moreover, the federal government has also enacted legislation permitting the use of DNA databases from certain convicted criminals. For example, under the *Criminal Justice Legislation*, the government can use reasonable force to collect DNA samples from convicted criminals.¹

Fears of Genetic Testing

Recent technological advances bring light to an individual's once dark and unknown medical future. Instead of only hoping for the best, people can now partake in genetic tests to determine their susceptibility of developing certain conditions later on in life. Yet, the majority of the population is foregoing the "benefits of new predictions, diagnoses, and therapies" because they do not have confidence in the privacy of their genes.⁶ As a result, those individuals that once served as medical research subjects are now unwilling to volunteer for studies. Consequently, without subjects to observe and test, the quality of research for future medical studies are reduced significantly, which is problematic for the future. One of the underlying reasons for this unwillingness and decrease in research subjects includes the fact that researchers refuse to be held responsible for the selling of database systems as well as stolen genetic information from database system breaches. For example, in the case that Tavani featured in *Implications for Personal Privacy*,⁴ Toysmart customers were given assurances that their personal information will be protected by the company's privacy policy. However, when the company filed for bankruptcy in 2000, they sold off databases containing customer information while believing that they were no longer bound by the old privacy policies. They based their justification on the fact that the company was no longer tied to prior contracts and that the database contents were now the sole property of a new owner.⁴

Privacy Concerns

Genetic data is difficult to keep confidential because a great deal of our medical information is stored electronically which makes it susceptible to misuse by third parties. This sort of data is very revealing about us because it discloses our complete genetic make-up. Many challenges exist in trying to conceal our DNA. We shed our genetic information on a daily basis. It can be easily acquired from a sealed envelope, a dirty facial tissue, loose hair on a comb, or even from a used drinking mug. Therefore, we will always be vulnerable to revealing our DNA to whoever tries to acquire this information. What is worse, DNA is easier to acquire than other medical information and, it can have more profound consequences for us.

In light of the ease of genetic accessibility, the use of this information raises many concerns to individuals for different types of reasons.

Discrimination by insurance companies: People fear that they will be discriminated against by insurers. Insurance companies could collect peoples' DNA data to decide who to insure and what to charge them. This would result in a certain proportion of the population that would become uninsurable and discriminated against based on their genetic background, something that they have little control over.¹

Employment discrimination: Genetic screening in the workplace is on the rise and could lead to discrimination against people who might be screened for future potential diseases. Also, employers have incentive to discriminate against current or potential employees based on their DNA as long as health insurance is provided through the workplace. Since medical screenings reveal the current or potential health complications people have, insurers will charge higher premiums to those who have genetics that are linked to undesirable traits.¹

Genetic Spying: Improving technology and the relative ease of accessibility to peoples' DNA could allow everyone to routinely check out other individual's genetic codes. This will pose as an extreme concern when genetic screening becomes commercialized. This will enable just about anyone to get a genetic test done for a low price.¹

Cyber Risk: Genetic information can easily be stored within any database. This becomes a critical challenge to professionals responsible for the privacy and confidentiality of patient health information. The cyber risks associated with the use of this information include: system vulnerability, system circumvention, and verification and enrollment fraud.⁷ These risks continue to be a growing concern in relation to the use of databases to store the mass amount of genetic information. If hackers have the capability to infiltrate these databases, they will be able to access our genetic information, and even worse, sell this information to anyone from commercial companies to market researchers and biotech laboratories.

Commercialization: The potential use of genetic information for commercial purposes is proving to be a problematic concern in recent years. For example, in 1991, Incyte Pharmaceuticals sold databases of genetic information to drug companies and researchers. This information was then used to market to certain populations that were more susceptible to specific health diseases.¹ And in the case of deCODE Genetics Incorporated, a genetic research company that accessed the DNA of the Icelandic population through their government's permission, the company commodified the Icelandic population's genetic information for commercial profits such as obtaining contracts with IBM to produce "gene-mining" software and a \$200 million contract with Roche, a Swiss pharmaceuticals company.⁴

Data-Mining

Data-mining of genetic information is an underlying threat to medical and health-related privacy. Genetic data-mining is used to manipulate recorded and stored data by finding patterns and relationships in data by forming hypotheses. Mining software is used to sift through DNA of large populations and, from there correlations of gene and gene variations are compiled based on gene samples and disease records. These classifications and correlations of designated group data are then used in the determination of things such as health insurance coverage or employment decisions. The individual has no say in how the data is processed and will not even be aware that decisions on their everyday lives were based on generalizations of group data. Also, databases are containing a wider range of information that can be easily accessible to a

greater amount of people who have other purposes for using it.⁴

Ethical Dilemma

According to the rights-based moral theory, “all humans have certain moral rights or natural rights.”⁸ Such rights include the right to life and the right to privacy. Rights based theories include positive rights, otherwise known as entitlement rights, which claims that others are obligated to provide us with the things that we are entitled to, such as jobs and health care.⁹ Additionally, this theory includes negative rights as well, which provides us with the freedom to do something without interference from others.⁹ One could apply this theory to genetic screening information in regards to employment and insurance practices. We have a positive right to health care and employment, as well as to privacy. We also have a negative right to have those things without interference from others. Third parties and the abuse of genetic information interfere with our rights to keep medical information private and it also interferes with our rights to apply for jobs that have reasonable insurance coverage. Therefore, unethical applications of genetic screening information directly violate our rights.

The Government and Genetic Privacy

Currently, there are only a handful of federal legislations that address privacy rights on the use of genetic information. As you can see from the chart below, current regulations are not enough to protect our genetic privacy against misuse by employers and insurers. Most of these regulations are broad-based legislations that protect only certain classes of people such as federal employees or members of a group policy plan. This evidently creates loopholes for employers and insurers to get around these laws.

| GOVERNMENT REGULATIONS ON PRIVACY & GENETIC DISCRIMINATION | |
|---|---|
| <u>Criminal Justice Legislation</u> | Limits the disclosure of stored DNA information to crime agencies, courts, and for defense purposes in criminal cases such as rape or murder. ¹ |
| <u>Privacy protection section</u> (in the Criminal Justice Legislation) | Contains a specific sectional addition of (42 U.S.C. sec 14135(e)) that states the FBI and all states accessing the index are required to dispose of DNA records of persons whose criminal convictions were overturned (42 U.S.C. sec 14135(d)). ¹ |
| <u>Litigation warrant and court authorization</u> | Gives judicial proceedings authorization to pursue the use of DNA as evidence in cases such as paternity suits. ¹ |
| <u>Health Insurance Portability and Accountability Act of 1996 or HIPAA</u> (Pub. L. No 104-191) | States that genetic information shall not be considered a pre-existing condition in the absence of a diagnosis of an actual condition. ¹ |
| <u>Executive Order 13145</u> | Forbids the Federal government from discriminating on genetic grounds. ⁶ |
| <u>The Daschle-Kennedy Bill</u> | Prohibits federal employers from considering genetic information in hiring, promoting, discharging and all other employment decisions. ¹ |
| <u>The HIPPA National Standards to Protect Patients' Personal Medical Records</u> | Regulates and helps protects medical records and other personal health information maintained by health care providers, hospitals, health plans and health insurers, and health care clearinghouses. ¹ |
| <u>Title VII of the Civil Rights Act of 1964</u> | Prohibits employers from discriminating on the basis of sex, race, national origin, religion, or color. |
| <u>Rehabilitation Act of 1973 and the Title I of the Americans with Disabilities Act of 1990 (ADA)</u> | Enforced by the Equal Employment Opportunity Commission (EEOC), offers a broader protection of genetic discrimination in the work place such as disabilities discrimination. ¹ |
| <u>The Genetic Information Nondiscrimination Act of 2005</u> | The act would have "prohibited discrimination in health insurance and employment on the basis of predictive genetic information." ¹⁰ But unfortunately, this bill was never enacted into federal legislation. |
| <u>Executive Order 13335</u> | Establishes the importance of the development and implementation of a nationwide interoperable health information technology. |
| <u>Executive Order 13410</u> | Requires Federal health programs to provide "meaningful, consistent information on both the quality and price of health care services." ¹¹ |

Questions Raised From Genetic Screening

Genetic tests provide detailed information that can be easily stored within many databases, which raises the question of how the government and researchers need to

manage and protect individuals' health-related data. Several social and ethical questions that HGP and genetic screening have provoked include:

1. How will privacy rights be affected?
2. What are the abuses of obtaining this information?
3. How are federal laws going to protect genetic information?
4. How will data-mining affect this information?
5. How will employers and insurers be held to ethical standards?

Genetic Privacy as a Universal Right

Your genes and DNA belong to you. They are your personal property and should be treated as so. But this is not the case in court warrants, DNA extraction from criminals, and even private research facility contracts. Criminals get their DNA extracted and recorded to databases. Court warrants force the use of gene information for litigations, and private research facilities disclose peoples' genetic data through publicly stored research results and publications. Once this information is collected, it is thought to be the property of the government and its databases, so it can be freely published in research articles. Furthermore, medical information is highly sensitive and reveals much about our identity. It should be given emphasis over communications privacy because "genes are private, not public, property."⁶ Communications such as corporate surveillance only addresses issues such as productivity, efficiency, and use of resources in the workplace; whereas the use of genetic screenings by employers and insurers are more personal and surveys our entire genetic background on a microscopic level.

Privacy is worth protecting because it is "an expression or articulation of a core moral value which is essential for human flourishing, and privacy provides a valuable shield that protects us against unwanted interference, intrusion, and inappropriate access to information about us."⁴ This brings up several important points on how an employer, insurer, and even the government should not have the ability to spy on anyone's genetic information without the person's permission. Imagine the possibilities if random individuals had unlimited access to all of your information,

including private genetic disclosures. Genetic privacy needs to be addressed as a universal right because everyone should have the right to protect and determine who has access to their DNA information. This kind of privacy is as vital, if not more so, as private property because it is potentially more invasive and revealing about our character than any other kind of technology.

Abuse of Information

The commercialization of genetic testing will result in additional privacy concerns on a microscopic level. Strangers are able to obtain another individual's DNA information by taking a discarded tissue or hair sample into a research lab for analysis. By 2010, scientists expect that the cost of obtaining this information will only be \$100.¹ Our private data will surely be compromised if and when this technology becomes a common form of identification that anyone has access to.

Likewise, since inexpensive genetic testing is on the brink of commercialization, it needs to be addressed with more conservative (or strict) federal regulations. Because it is impossible to prevent genetic screening material from coming into the hands of those who want it, it is imperative that federal laws regulate those who extract the data. All of the potential abuses listed above raise the question, "Do current laws protect people from this abuse?" Current federal laws, previously mentioned, slightly suggest that we might be protected by these regulations.

Additionally, the use of genetic testing raises questions of abuse of medical and genetic information. There is a growing concern that the accessibility of an individual's genetic data will be a basis for discrimination in cases such as employment and insurance coverage. Also, some primary concerns are that insurers will use this information to deny, limit, or cancel insurance policies and that an employer will use the information against their current workers or to screen potential employees.¹ An example of this kind of misuse of genetic data can be seen in the case of the Burlington Northern Santa Fe Corporation lawsuit. In this court case, a railroad worker was threatened with an investigation for insubordination if he refused to get "additional, objective medical information" to determine whether or not his carpal tunnel syndrome was work-related.¹² When the railroad worker's wife, a nurse, called to inquire about

the list of lab tests that were to be done, the medical liaison for the company refused to release the information. This is just one example of a violation to people's privacy and the potential misuse of genetic information against employees.

Moreover, the increase of employment related genetic screenings may not be as adequate as previously thought. For example, although employers are becoming more interested in using genetic information to determine the health and cost of current and potential employees, the results found in such genetic tests may actually be insignificant to the company. Genetic tests may reveal genes on different chromosomes that indicate an elevated probability of specific diseases, such as Alzheimer's. However, such genetic predispositions are not always job related. For example, Alzheimer's disease typically develops at the average age of 72.8 years old in comparison to the average retirement age of 59.¹³ Evidently, employers will not be affected by these future medical costs, assuming that the individual does in fact develop the disease. An article from the Wall Street Journal mentioned that "most such genes have their effect only if an environmental factor is also pushing in the same direction."⁶ Thus, the effects of genes are not entirely inevitable as outside factors often determine the development of some diseases and as time progresses, medical technology is developing more ways to further prevent and/or reduce the effects of certain ailments.

Genetic fatalism is a term used for those individuals, and in this case employers, that have a "grossly exaggerated view of the power of genes."⁶ This view holds that "we cannot avoid specific genetically determined outcomes, no matter what we do or what happens to us: our fate is in our genes"¹⁴. Employers that believe in this point may neglect to hire any candidate that has a genetic link to some sort of ailment, despite that individual's potential performance value. Similarly, insurance companies may find it necessary to increase the insurance rates of any person with unfavorable genetic predispositions or deny them coverage altogether. In all reality, "we can overcome the effects of genes."⁶ Comparable to social factors, genes are conditional and subject to outside forces.⁶ Employers and insurers need to have a more practical outlook on the information found from genetic screenings as the results are not inevitable. It is irrational for an employer to deny a healthy person employment or for an insurer to base coverage on a genetic predisposition to developing a disease in the future.¹⁵ If this

approach was applied to everyone, no one would have a job or insurance because the majority of people would have some tie to an assortment of genetic predispositions.

Furthermore, employers should consider how a given condition will hinder job performance and if the employee's value outweighs the medical and company costs associated with the hindrance. Suppose a genetic test for a highly skilled employee reveals that she is susceptible to colon cancer, which she later develops, but the cancer was caught in the early stages so the treatment enabled her to fully overcome the disease. Taking only two weeks of unpaid leave to recover, the individual returns to work, and her performance is in no way affected by her past condition. Should the company fire this valuable employee upon learning of her diagnoses? Or would it be more of a burden to find a new employee that possesses maybe half the skill set of this individual, simply to avoid higher insurance costs? What is this employee really worth? Moreover, employers must determine if the potential genetic findings are even relevant to job duties and question if such revelations will make any practical difference to job performance. Individuals with disabilities are protected under the American with Disabilities Act of 1990 which permits reasonable accommodations to be made, as long as the person can perform the necessary set of duties.

More Federal Regulation Needed

The protection of federal laws, such as that offered by the HIPAA, is limited. This federal law does not prohibit insurers from increasing rates based on genetic test results nor does it cover individuals who are not in a group plan. This poses a big problem considering the fact that 46.6 million Americans do not have health insurance.¹⁶ Also, it does not protect against discrimination by employers who could be screening for specific genetic discrepancies. The legislations discussed in this paper do not specifically address genetic testing in relation to privacy but it does discuss medical examinations and inquiries in relation to terms of pre-employment, pre-placement and post-placement levels. Again, it does not address the larger issue at hand. Under current laws, pre-employment medical screenings are prohibited unless the employer makes a conditional job offer on the successful completion of the examination. But what if it wasn't "successful?" The employer is under no obligation to indicate why the individual was not

hired nor does he have to tell the individual about his test results. The information generated by the tests does not have to be disclosed to the individual who took the test.¹ This raises ethical concerns about the privacy rights of the subjects that underwent such screenings.

Furthermore, the 2005 Legislative Notice concluded its administration position with, “the Administration wants to work with Congress to make genetic discrimination illegal and provide individuals with fair, reasonable protections against improper use of their genetic information.”¹⁵ But the problem is that there are no strong regulations in place for these protections. Although the previously mentioned federal regulations propose some measures of protection against disability-related genetic discrimination in the workplace, none of these statutes explicitly address genetic information in relation to those who have access to the genetic databases. Existing laws also fail to address how the information can be used by employers and insurance companies, and it does not address the issue of managing and protecting genetic information from data-mining. Moreover, the bills that specifically address the use of genetic information, such as the Genetic Information Nondiscrimination Act of 2005, were never enacted. Therefore, existing laws, as discussed in the government regulation chart, fail to address how the information can be used by employers and insurance companies, and it does not address the issue of managing and protecting genetic information from such applications such as data-mining.

Data-Mining of Genetic Information

The use of data-mining by employers and insurers is not entirely adequate because it makes generalizations about groups of people and it uses this information to predict results for individual cases. The use of profiling in data-mining constructs groups on the basis of non-distributional profiling and this information is used by companies to make decisions about individuals and groups without their knowledge or permission. For example, in Custar’s hypothetical example, data-mining can be used to correlate the data of populations who own red cars and having colon cancer.⁴ This information, once collected, is then used by health insurance companies to raise the

insurance premiums or deny insurance to people based on the fact that their clients fit into the correlation between red cars and colon cancer. There is no just connection between these two records yet this is a real problem that is occurring today. Companies are making decisions about people based on information that have no relevant relationships. The use of these generalizations will discriminate against those individuals who are judged and treated on the basis of belonging to the “wrong category of persons.”⁴

Evidently, the use of aggregated data in data-mining cases raises huge concerns about one’s privacy. Despite the fact that individuals have legal rights over personal data as it applies directly to one’s self, a person does not have the same rights over the personal information that is derived from that data.⁴ This creates a problem especially when databases are sold to or acquired by other organizations. It brings to question whether or not the new company has a right to utilize the personal information stored in these databases. The individuals at risk never consented to have their information used by this different organization.

Therefore, the creation of group profiling and aggregated data is problematic in the sense that aside from group commonality, the properties and characteristics assigned to members have no relevance for the individuals.⁴ Such generalizations lead to arbitrary assumptions that limit and penalize people in terms of employment practices and insurance rates.

Importance of Ethical Standards

Employers and insurers should be held to the rights and the virtue approach of ethical standards. Under the rights approach of ethical standards, “the ethical action is one that most dutifully respects the rights of all affected,”¹⁷ which, in application to our arguments, mean that employers should respect their worker’s rights and health insurers should respect the rights of their policy holders.¹⁷ The rights approach expands to all rights including that of genetic medical information privacy, its confidentiality, and informed consent to use this information. According to this standard, people should have the right to maintain their medical and health related privacy. Employers and insurers should have to obtain consent from the individual to request a testing, instead of making

it a requirement. Also, people should have the right to keep their medical data confidential and employers and insurers should acknowledge that the data produced by genetic screening is sensitive and access to this information should be limited to parties authorized to receive it.¹⁸

Moreover, under the virtue approach of ethical standards, “the ethical action is the one that embodies the habits and values of humans at their best” and includes virtues such as fairness and integrity.¹⁸ The virtue approach should be used to ask the question, “What kind of employer would one be if one decides to use genetic screening in the workplace?” and “Would the action of requiring genetic tests be consistent with the employer acting at his best for the best of his associates?”

Conclusion

Without genetic privacy protection we are all vulnerable to employment discrimination and group profiling by insurance companies. The lack of federal regulation over health-related information allows this data to be shared, exchanged, sold, and/or aggregated by data-mining without the patient’s knowledge and permission. That data can then be acquired by employers and insurance companies to be used against individuals. The personal information obtained from genetic testing can be made public through electronic accessibility which poses a privacy threat to health records. Ultimately, unauthorized accessibility of health information violates both our negative and positive rights to health care, employment, and privacy, as noted in the rights based theory.

Furthermore, job requirements will be based on health attributes rather than skills, knowledge, or experience and employers may hold misguided views of what their ideal candidate’s genetic make-up should look like. Consequently, organizations will miss out on talented individuals that may add value to the company. As a result, the economy, and society as a whole, will suffer from the exclusion of such gifted people. Also, health insurance companies will have the power to take advantage of this information to control and manipulate benefit costs for unfavorable subscribers. So, as long as genetic information exists and is accessible to employers and insurers through databases, privacy rights are susceptible to interference and misuse by third parties.

Therefore, the gathering of genetic information will inevitably lead to exploitation in the forms of stigmatization and discrimination from employers and insurance companies. That is why it is extremely important that the federal government enacts legislations that directly address the use and commercialization of genetic information as well as regulate the protection of this very private and personal information that could be used in harmful ways against its original owners. In addition to more government intervention, there is also a growing need of more ethical standards that employers and insurers should abide to. By using ethical standards as a guide, employers and insurers can use a more effective means of evaluating current and potential employees and determining plan holder options while upholding a standard of fairness and responsibility.

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