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Identity Theft: Genetic Privacy

Genetic privacy and security is a very real issue today, especially with the advent of new technology and companies like AncestryDNA and 23andMe. While these companies advertise themselves as a fun way to learn about your family history or to learn more about your health, the voluntary (and potential involuntary) distribution of this information can affect the privacy of not only the individual, but of the individual's close family members and future generations. Genetic information, if misused, can potentially be stored and utilized without consent by law enforcement; by employers with the potential to discriminate against employees or potential employees; by private corporations to develop or advertise products; or even worse, by private individuals with bad intent who seek to "surreptitiously" obtain personal information for the purpose of discovering sensitive or embarrassing personal information about others.[1]

The National Institute of Health's National Human Genome Research Institute has long recognized the importance of genetic privacy where genetic information is being used for research, clinical or other purposes.[2] Traditionally, genetic information collected for research purposes has been stored anonymously to protect privacy. However, genetic information by definition is unique to each individual, which makes it challenging to truly anonymize.[3] Through the advent of new technology, even genetic information stored in databases for research and clinical purposes, without personal information like names or other obvious identifiers, are subject to risk.

In 2013, a researcher affiliated with the Massachusetts Institute of Technology was able to identify five individuals from a DNA database using only their DNA information, age and the states that they lived in – *in a matter of hours*.[4] Not only was the researcher able to track down the individuals, he was also able to find the individuals' close relatives.[5] Even more astounding, in 2008, a research study was proposed by geneticist, David W. Craig, whereby DNA would be collected from discarded needles of intravenous drug users to establish a database to look for viruses or DNA information and to determine a particular individual's DNA from the database of genes. The result was shocking – Dr. Craig was able to develop a method to identify an individual even if that person's DNA was only 0.1 percent present. Moreover, DNA is not the only type of genetic material from which individuals can be identified. It was discovered at Mount Sinai School of Medicine that RNA data could not only be used to identify individuals, but could also be used to develop a "profile" of an individual, including age, weight and certain medical conditions, such as diabetes or viral infections like HPV or HIV.[6]

Discussed further below are just some of the ways that new genetic privacy concerns are being raised.

Genetic Information and the 4th Amendment

Government collection of genetic information is subject to the 4th Amendment protection against unreasonable search and seizure. The federal government's collection of genetic information expanded rapidly more than a decade ago. In 2000, Congress passed the DNA Analysis Backlog Elimination Act of 2000, which required certain felons – primarily violent felons who were convicted of murder, voluntary manslaughter or sexual abuse – to provide DNA samples for inclusion in a national database.[7] The database is used for law enforcement identification purposes; in judicial proceedings if otherwise admissible; for criminal-defense purposes; and for a population-statistic database for identification research, or for quality-control purposes, if personally-identifiable information is removed.

Just four years later, Congress passed the Justice For All Act, which expanded the class of felons to all felons of federal crimes.[8] This expansion has been upheld by federal appellate courts.[9] While this may be

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a reasonable invasion of privacy directed toward a relatively small group of the population, the limits of the 4th Amendment relative to genetic information are yet to be specifically defined by the judiciary.

Genetic Discrimination

Discoveries in genetics will likely advance to a point where every individual's genome will reveal vulnerability to some health problem. Obviously, some vulnerabilities will be more serious than others. Needless to say, the advancements in the use of that information, both beneficial and exploitive, will keep pace with the science of genetics itself.

The current legal protections against genetic discrimination are fairly narrow. On the federal level, there is the Genetic Information Nondisclosure Act (GINA), 42 USC Section 2000ff-1. However, that statute only prohibits discrimination in the context of employment and health insurance. There are notable exceptions to both categories. In the context of employment, GINA does not apply to employers with less than 15 employees or the U.S. military. In the context of health insurance, it does not apply to individuals who receive health care through the Veterans Administration or the Indian Health Service.

Some states offer broader legal protections against genetic discrimination. For example, California protects genetic information from discrimination in housing accommodations, as well as employment (Cal Gov Code Section 12920).

Thus, there remain many areas where genetic discrimination is largely unchecked. One of the most notable areas is life insurance. In the event of an untimely death, life insurance is used not only to help a dependent cover everyday living expenses or cover outstanding debts, but also to pay for funeral and burial costs that can easily run into the tens of thousands. There are currently no legal safeguards to ensure individuals are not discriminated against based on their genetic information regarding this common place benefit.

Commercial Use

Although it may seem innocuous to send out your DNA to sites like Ancestry.com and 23andMe, a closer look at the terms and conditions for companies like these may make you think twice. One potentially frightening reality – the terms and conditions when sending out your DNA are often broad, with testing companies claiming ownership of your DNA sample and the analytical information they obtain from it, or in the alternative, claiming full rights to transfer, process, analyze or communicate your genetic information to others for research and/or product development.[10] In 2012, 23andMe did just that when it announced that it had procured a patent (with exclusionary rights) for "Polymorphisms Associated With Parkinson's Disease" stemming from the data it had aggregated from its customers.[11]

Surreptitious Use of Personal Information

With the development of faster and more inexpensive ways to analyze DNA, more concerns are raised about what is known as "abandoned DNA" (like the DNA on the tissue you throw away after you blow your nose).[12] A former romantic partner with a grudge or a "frenemy" interested in causing mischief could potentially collect your abandoned DNA and have it analyzed for sensitive personal information, including embarrassing health information or to reveal paternity. Not likely to happen, you say? Well, this was the case for one multi-millionaire Hollywood producer, Steve Bing, whose DNA was obtained from dental floss stolen from his trash and used to prove paternity by a former lover.[13]

Final Thoughts

Much of the focus of future privacy concerns is directed to computers, or other electronic devices, and the data they store as a consequence of human interaction. However, as set forth in this article, innovation in the extraction, analysis and storage of specific genetic information may be even more consequential. Complete privacy of genetic information may have been left behind in the 20th century. P

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8 *Id.*

9 *Id.*

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