CENTER FOR PRACTICAL BIOETHICS
GUIDANCE AT THE CROSSROADS OF DECISION

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The Ethics Dispatch

> "Functioning as our better selves leads to better outcomes for patients and everyone."
> -- Tarris (Terry) Rosell, PhD, DMin, HEC-C

Hot Topic

Genetics and Life Insurance: Should Your DNA Define Your Coverage?

In a world where genetic testing has become increasingly accessible, a new, complex issue is emerging: the ownership of genetic data and its implications for privacy and fairness.

As more people turn to services like 23andMe or Ancestry.com, the results of these at-home genetic tests could soon determine your eligibility for life insurance and the premiums you'll pay. While genetic tests can provide valuable insights into our health, they also raise questions about the ethics of genetic ownership and the risks of discrimination.

What about GINA?

"What about the Genetic Information Nondiscrimination Act of 2008 (GINA)?" you might ask. Good question, dear Reader, but GINA's protection does not extend to life insurance. As documented by the American Society of Human Genetics (ASHG), "[t]here are a few notable limitations to GINA's protections. With respect to insurance, GINA's protections are limited to health insurance: it does not cover life, disability, or long-term care insurance." (ASHG.org, 2025).

Currently, life insurance companies can access genetic information through your medical records or purchase it from third-party data providers, sometimes without your explicit consent. As an article written by Zack Sigel for Investopedia explains, "Insurers can use the results of that test to determine whether or not to offer you coverage and for how much. The data helps them statistically predict the likelihood that you'll develop a medical issue that could shorten your life expectancy." (Sigel, 2025).

This creates a situation where a seemingly personal and private matter -- the details of your DNA -- becomes a bargaining chip in determining your insurability. If your genetic code suggests a predisposition to certain diseases, such as cancer, you could face higher premiums or even be denied coverage altogether. Conversely, a healthy genetic profile might work in your favor, lowering costs and making coverage easier to obtain.

Who Owns Your Data?

Obviously, this system is fraught with ethical dilemmas. The issue of genetic discrimination is particularly concerning, as it often overlooks the fact that genetic predispositions do not guarantee that an individual will develop certain conditions. For example, as Mark A. Rothstein, a bioethics expert, states, “insurers who deny or limit life insurance coverage based solely on a BRCA1 or BRCA2 mutation are not accounting for people who take preventive measures against developing breast cancer or who might never have developed it in the first place.” (Sigel, 2025). Insurers may use these genetic markers to unfairly assess risk, punishing individuals for factors beyond their control. Furthermore, the fear of discrimination could drive people to forgo genetic testing altogether, potentially limiting their access to essential life insurance protection.

There’s also the matter of ownership. Who truly owns your genetic data? Many people may not fully understand the implications of submitting their genetic information to testing companies, which often retain the rights to sell or share this data with third parties. As Sigel’s article points out, “if you use a self-testing kit like those from 23AndMe or Ancestry, your information might be shared with third-party commercial organizations.” While some services claim to protect your privacy, the reality is that your genetic information may be used in ways you never anticipated, including assessing your eligibility for life insurance.

Safeguarding Against Genetic Discrimination

Until laws evolve -- perhaps by expanding protections like the Genetic Information Nondiscrimination Act (GINA) to include life insurance -- individuals are left navigating a landscape where their very DNA can be used to determine their financial future. As Rothstein notes, the use of genetic information in life insurance underwriting may result in “adverse selection,” (Sigel, 2025) where individuals who fear genetic discrimination may avoid applying for life insurance altogether. This creates a ripple effect that impacts both consumers and insurers.

As we move forward into this genetic age, the conversation must shift towards not only protecting privacy but ensuring that genetic data is used ethically and fairly, without penalizing individuals for factors outside their control. After all, our genetic makeup should not define our opportunities in life, nor should it dictate how much we pay to secure a future for our families.

Sources

ASHG.org, 2025
Sigel, Zack. (January 6, 2025). Can Your DNA Change How Much You Pay for Life Insurance? *Investopedia.com*

Bioethics in the News

Bioethics Gone AWOL: The Dangers of Creating Designer Children | American Council on

Unethical moments in U.S. medical research history | PBS NewsHour Classroom

Using AI to choose embryos in assisted reproduction raises significant ethical worries

Science and Health | MSN

Case Study: Genetic Testing Ethics

Mother Refuses Genetic Test

Emma is a five-year-old girl who was admitted for aggressive seizures, neuro storming and palliative care. She has had an extremely difficult life due to severe medical conditions, possibly resulting from injuries sustained at birth.

Emma has never been able to gain consciousness, open her eyes, or engage with her family. She has experienced uncontrollable seizures throughout her life, and her health has been in a continuous decline. Her mother has frequently returned to the hospital for admissions. While her prognosis has always been grim, this admission appears to be her last. Emma's mother has requested palliative care to make her as comfortable as possible.

The situation is further complicated by a legal issue. Emma's mother is currently in the process of filing a malpractice lawsuit against the hospital. This has created a tense environment, with hospital staff hesitant to engage with her.

Yesterday, the hospital geneticist discussed the possibility that Emma's medical conditions may not be the result of a birth injury but rather a genetic condition. If this is the case, there are therapies that could help treat Emma, though these would be palliative and not curative. While it is unlikely that a genetic condition is the cause, it remains a possibility.

The geneticist asked Emma's mother if the hospital could conduct a genetic test. Initially, Emma's mother agreed. However, after consulting with her attorney, she later informed the hospital that she would refuse the genetic test.

Ethics is consulted.

Ethical Musings

Know Thyself:
Genetics, Mereology and the Complexity of Identity

"Know Thyself."

It is deep, ancient wisdom that a person should know who he or she is before they can fully function in the world. How can you know anything if you do not even know yourself? But what does it mean to be who you are? This has been a question of interest for philosophers for centuries, with several different beliefs and approaches.

DNA as a Part of You

One of these approaches is mereology, from the Greek*μέρος*, meaning 'part,' which is the theory of parthood relations—or the relations of a part to a whole and the relations of part to part within a whole. To know what something is, you need to only study the individual parts of the object. If you know all the parts, then you understand the whole.

Applied to the human experience, if we want to understand who someone is, including yourself, then we should learn about the individual parts that make you up. This would imply that to know yourself means only knowing about the parts that make you. You need to understand your liver, kidneys, stomach, heart, etc., as well as your skin, muscles, and hair. Mereology also follows this down as far as you can go, meaning this applies to the microscopic level as well—down to your molecular level. Your individual cells are just as much you as you are you. Then, logically, to know your cells, you would need to know their parts, including your DNA.

From a mereological perspective, your genetic information is not you, but rather a part of you. As Pietruszczak (2014) argues, "a biological subunit of a cell is not a part of the organism of which that cell is a part." This can create difficulties, particularly due to the ambiguity of the word "part." A way that many philosophers think about this is by asking what counts as an essential part: If you took it away, would the object remain the same? If you were to have your gallbladder removed, you would likely still consider yourself "you," just a you without a gallbladder.

Not You Without Your DNA

Your gallbladder is not what makes you yourself, but with DNA, it can be difficult to distinguish these differences. As Varzi states:

> What counts as a biological subunit of a cell may not count as a subunit, i.e., a distinguished part of the organ, but that is not to say that it is not part of the organ at all. Similarly, if there is a sense of 'part' in which a handle is not part of the house to which it belongs, or my fingers not part of my team, it is a restricted sense: the handle is not a functional part of the house, though it is a functional part of the door and the door a functional part of the house; my fingers are not directly part of the team, though they are directly part of me and I am directly part of the team.

Your genetic information, your DNA, is a functional part of your body, and thus your self. You would not be you without your DNA. And if your DNA were different, then you would be different, thus making your DNA an important part of what makes you. From this standpoint, a person's DNA should be seen as uniquely theirs.

More Than Your DNA

But this approach feels like it is missing something. Many would believe that you can know yourself without having to know your parts, including your genetic information. You can have a strong sense of self without knowing anything about your heart, liver, blood, or your DNA. For thousands of years, people have struggled with self-identity without ever knowing about their cells or DNA. Did they not know themselves?

Your genetic information will forever remain an important aspect of you, but it is not the full story. You are more than just your DNA, just as you are more than just your individual liver. They are parts of a much larger whole.

Sources

Varzi, A. (2019). *Mereology*. The Stanford Encyclopedia of Philosophy (E. N. Zalta, Ed.). https://plato.stanford.edu/archives/spr2019/entries/mereology/

Pietruszczak, A. (2014). A general concept of being a part of a whole.*Notre Dame Journal of Formal Logic, 55*(3), 359–381.

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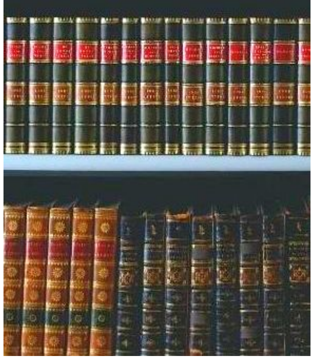

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