

Ethics

A perspective on Cellout.me by bioethicist Eline Bunnik, affiliated with Erasmus MC, Department of Medical Ethics and Philosophy of Medicine.

Appreciating DNA

On the moral value of one complete human genome

Over the past decades scientists all over the world have placed strong bets on genome research and genome technology, under the assumption that the genome contained the blueprint of human life. They thought that, once they were able to 'read' DNA, they would be able to predict where our human weaknesses lie, which diseases will affect us, what it is that will eventually kill us. Human kind would gain insight into its future. But can we truly know our future, and do we really want to? How can we live, for instance, knowing that we will develop Alzheimer's disease, a disease for which there is no cure? Is getting to know our own DNA really such a good idea? What moral value does the genome have for us?

If we ask questions about the 'moral value' of our DNA, what kind of value are we talking about? At least three kinds of values are of relevance: informative value, worthiness of protection, and symbolic value.

If we determine the sequence of the three billion base pairs and then look at them, they do not tell us anything. The sequence looks more or less like this:

CTCCTCCTCATCTTCGTACGGTCTCCTCGCTTCGCTAGCTCGCTTGCTTGCTGG.

A sequence is nothing but data: it is not informative yet. The genome gets its informative value through analysis and interpretation. We can only predict hereditary traits, physical traits, or risk of diseases, if we can 'read' the genome.

Though scientists have become better and better at reading the genome, they have not become much wiser. Once read, the genome turns out to contain much less usable information than previously assumed. For the most part, the predictive value of the sequence is rather limited. Genetics has turned out to be extremely complex – a foggy crystal ball in which one cannot discern one's future. Still, there is some usable information to be found in the genome, and more and more of it. For example, we all carry 3 or 4 recessive conditions that we can pass on to our children. Numerous markers in our DNA can indicate possible health risks. Some people have rare mutations that will almost certainly cause diseases later on in life. Not every genome is as tell-tale as the next.

The human genome can thus be of informative value – it could, for example, be useful for the promotion of health. DNA may also be of informative value for another party,

such as an insurance company or an employer, who may refuse to hire somebody on the basis of genetic risks. DNA can be used in immoral ways. These risks apply not only to you yourself, but also to your family members. If your genome is analyzed, your siblings may accidentally and perhaps regrettably find out about certain conditions that may also affect them. Your DNA does not belong solely to you. When it comes to decision-making about your genome, your relatives should be involved in the process.

DNA is worthy of protection. This worthiness of protection depends, among other things, on the person. It is said that the security detail of the president of the United States always erases any traces of DNA he leaves behind, wherever he goes. We all lose hairs, skin cells and mucous membrane cells throughout the day. We leave our DNA everywhere we go; on door handles, glasses and acquaintances' hands. Because the traces of DNA we leave behind cannot be read easily, we do not have to protect them on a daily basis. But what about, for example, my own genetic test results – including dozens of health risks – that are stored at the commercial American company that has analyzed my DNA for me? The company holds my readable DNA. This is DNA that I should protect. Protecting a genome today mostly consists of monitoring access to the 'read' genome, and ensuring that these three billion pairs of data will not fall into the wrong hands. You can protect a genome by guarding its digital translation, thus protecting the person behind it.

Then there is the symbolic value of DNA. I could keep my baby's first DNA sequence in the same way that I've kept a lock of his hair from his first haircut. The genome as a symbol for a person, then, has value if that person is important to me. There are people who are willing to pay more than half a million dollars for the guitar that John Lennon used in 1966. This guitar is an icon; possessing it brings the owner one step closer to his idol. In the same way, I could become closer to my loved ones if I possessed their DNA, if I knew their sequence. But what does the complete genome of a 'regular other' mean to me?

Every person's DNA is unique. The genome is an identifier in itself; forensic DNA-research requires only about ten genetic markers to create a unique, identifying DNA-profile. A genome is more a person's 'own' than, for example, their name. It contains all the instructions for the construction and the functioning of the body. In the same way that a fully-grown tree is determined by its seed, a fully-grown body is determined by its DNA. In theory, scientists should be able to generate a new human body from one single cell, on the basis of one DNA-molecule: a clone. My genome, that endless chain of A's, T's, C's and G's: that is me.

DNA, in sum, has moral value. It is a carrier of information that can help promote health, but it can also lead to genetic discrimination. DNA is worthy of protection, and it is a symbol for the human being. But how does one express the moral value of DNA? Can it be converted to a monetary unit? Could we possibly conceive of something like a moral selling price in relation to the cost price? You could think of DNA as a digital version of a person. If you guard his genome and keep it, you can save him from obscurity, and maybe, one day, bring him back to life again. How much is mankind worth to me? How much is it worth to you? DNA is mysterious and ordinary, unknown and familiar at the same time. But above all, the value of the genome is personal.