

# Genome Sequencing

**1. Health Care and the Human Genome:** There is an interesting worry in the vicinity of the genetic engineering debate: How will the ever-lowering costs of sequencing DNA affect the health care industry?

## **Should we have this information AT ALL?**

The first question we might ask is, Should we allow **patients** and their **physicians** to have access to our genetic information? Here are some reasons both for and against:

Yes: we should have access to this information:

Sequencing the human genome can help to save lives. For instance, (1) if you discover that you are genetically at risk of getting cancer or heart disease, you might be able to change your life habits in order to reduce the risk as much as possible. Or, (2) if physicians discover which gene is responsible for your illness, they will have the information they need in order to more effectively prescribe the right treatment. Or, (3) if you discover that you are a carrier of a genetic disease, this may help you to make appropriate decisions about whether or not to have children.

No: we should not have access to this information:

Imagine that you are told that you will inevitably die of long and painful death, due to a genetic, neurologically degenerative disease. How will this affect your life? It might make you perpetually live in fear, or cause your family to disown you or feel uncomfortable around you as they are “just waiting for you to die”, or lead potential mates to not want to have anything to do with you. Such information can be HARD to handle. In the end, it may prove too psychologically damaging to individuals.

## **Should 3<sup>rd</sup> Parties Have This Information?**

Here is an even more interesting question: Should our genetic information be available to **third parties**, such as insurance companies or employers? Here are some reasons both for and against:

No: insurance companies and employers should not have access to this information:

(1) Discrimination: This country has a deep history of discrimination. Perhaps the biggest fear concerning the sharing of genetic information is that individuals will be **discriminated against** on the basis of their genes. Discrimination is any act of giving some preferential treatment or consideration over others based solely on

the intrinsic (i.e., unchangeable) features of the persons in question. But, this is exactly what we can expect, should insurance companies have access to genetic information (for instance, individuals may be denied insurance coverage on the basis of their genes, or forced to pay exceptionally high or even unaffordable premiums; others may be denied a job because of their genes; and so on). There is a real danger that a hierarchy of social classes would emerge, based on genes, where those with the "purest" or "best" genes are given preferential treatment.

- (2) Irrelevance: While some genes pretty much guarantee that one has, or will have some disease or other, with other genes it is not so clear what the implications are. It is one thing for an insurance company to make an assessment about insurance premiums based on a PRE-EXISTING condition. It is quite another to make an assessment based on a "PRE-EXISTING **DISPOSITION**" to a condition. What does "pre-disposed" even mean? It might be a long time before we figure out that some genes pre-dispose individuals to some disease with only a 10% probability of occurrence, while others do so with a 90% probability, and so on. Until then, it is unclear how relevant most genetic information should be. Nevertheless, employers and insurance companies are likely to use any excuse they can do deny employment or coverage (even if it is mis-information).

Yes: insurance companies and employers should have access to this information:

- (1) Economic: If patients DO have access to their own genome results, but insurance companies do NOT, the effect will probably be that healthy people will sign up for only the minimum, cheapest insurance policies, covering accidents and so on. Those pre-disposed to become sick, on the other hand, will be the ones taking out more expensive insurance policies so that their insurance carrier will have to cover nearly all of their costly future procedures. Ultimately, the result is that insurance companies will be bankrupted.
- (2) Precedence: Insurance companies already have access to a lot of our medical information, such as cholesterol levels, body mass index (BMI), family history, results of tests for diseases, and other pre-existing conditions.

In short, the arguments AGAINST sharing genetic information with insurance companies is, seemingly, based on what has come to be known as "**exceptionalism**". This is the view that genetic information is somehow "special", or DIFFERENT than the other sorts of information that are ALREADY shared with insurance companies. But, what reasons might we have for such exceptionalism?

**2. Exceptionalism:** Let's take a closer look at exceptionalism. As it turns out, the government has already taken steps to ensure the confidentiality of our genetic information. The [Genetic Information Non-Discrimination Act \(GINA\) of 2008](#) prohibited the sharing of genetic information with third parties. This is an indicator that even the government takes an "exceptionalist" stance, believing that genetic information is somehow "special".

Here are some traits that genetic information has, which no other sort of information has (at least, not ALL of these in combination):

- It is a unique identifier
- It is predictive of future disease
- It is passed vertically (from parent to child)
- It can be used to discriminate
- Knowing it can be psychologically damaging
- It can be collected from small samples, and without someone's knowledge

But, doesn't family history have all or most of these qualities? If it is permissible for insurance companies to use family history to discriminate, how is the use of genetic information any different?

Ruth Wilkinson argues that it is only because we have elevated genetic information to the "mystical" or "spiritual" realm that we revere it so much more than all other information. We see it as revealing "**who we really are**", or, as Bill Clinton described it, as being "**the language God used**" to create human beings. As such, genetic information deserves some additional respect that no other sort of information deserves. But, Wilkinson says, these ideas are leading our intuitions astray, and should be cleared away so we can think about this issue objectively.

DNA is not "who we really are": Those who think that our DNA (or, "nature") represents our true identity are confused. Genetic make-up only accounts for SOME of who we are, or what we are like. But, experiences (or, "nurture") make up just as much of who we are, if not more. For instance, consider two identical twins, who share the same DNA. Twins often have their own distinct, even radically different, personalities. Certainly, they do not share the same "identity".

The confusion is being made is called "**genetic determinism**", which is the view that our genetic make-up COMPLETELY determines who we are, and what our lives will be like. But, this is false. And, furthermore, if it were true it would lead to a terrible outlook on human freedom, and care for others. For instance, we would no longer want to "waste our time" helping a drug addict with the disposition to addiction, for they are a "lost cause", DETERMINED by their genes to act in a certain way.

Question: Is it possible that genetic information is different because no one has CONTROL over them? (But, then, perhaps family history should never have been given to the insurance companies either, since we have no "control" over this either?)

The Unfairness of Exceptionalism: Consider the following two cases, slight variations on a pair that Wilkinson gives:

- **Anna:** Anna has a family history of heart disease. But, she has not had a genetic test for the condition. Furthermore, she is overweight, smokes, drinks heavily, and does not exercise, and her physician deems her to be in poor shape, physically.
- **Bertha:** Bertha has no family history of heart disease. Furthermore, her physician deems her to be in great physical shape. She exercises, eats sensibly, and does not smoke or drink. However, she has a gene that disposes her to heart disease with near 100% probability.

Assume that Anna and Bertha have exactly the same likelihood of getting heart disease (i.e., near 100%). If Bertha undergoes no genetic test, or if she does but insurance companies are not allowed access to it, current practices dictate that Anna's insurance premiums will be very high, while Bertha's insurance premiums will be very low. But, if they have exactly the same likelihood of getting heart disease, it seems unfair to make Anna pay more, while Bertha pays less.

If this seems unfair to you, then perhaps there is nothing "exceptional" about genetic information, and so we ought to reconcile the injustice. Now, we COULD simply insist that insurance companies should not have access to ANY of this information, and should treat all patients equally.

Another solution is to pass legislation allowing insurance companies access to genetic information. Of course, some sort of legislation would need to be passed to ensure that this insurance was used in a "just" or "fair" way. Wilkinson proposes what she calls "**legislating for fairness**". It seems that her two primary suggestions are to either opt for Nozick's proposal or Rawls's:

- (1) **Actuarial Fairness (Nozickian):** Each individual should be responsible for the risks that they bring to the insurance pool. This would likely entail much higher premiums for individuals who have genetic pre-dispositions which make it likely that they will require expensive treatments. This view is fair to the insurance companies, as well as healthy individuals who are buying insurance. For, on this proposal, insurance companies would be informed enough to make better decisions about premium rates, and in turn this would "punish" healthy

individuals less, since they will not be “subsidizing” sick individuals as much. In this sense, the proposal can be seen as Nozickian, since it relies on the idea that it is unjust to “re-distribute” wealth by requiring healthy individuals to pay a lot into the system so that the sick may benefit from it.

- (2) **Fairness as Maximizing the Worst Off (Rawlsian):** Another proposal takes its cue from Rawls. Imagine, once again, that you are behind the veil of ignorance, and that you were told that a significant number of people in the society you were about to be placed in were going to require expensive medical treatments. Would you want a system where the sick are forced to pay extremely high insurance premiums, or would you prefer a system where everyone paid a certain (somewhat high, but not EXTREMELY high) amount, and everyone’s treatments were covered equally? We may, perhaps, prefer the latter system. [Would you?]

(Note that socialized medicine would, in theory, achieve this result; namely, every citizen pays taxes into the system based on income rather than genetic predispositions, and in turn, everyone is guaranteed treatment—even those who could not have otherwise afforded it.)