Recommendations for genetic privacy policies together with some chosen cases for discussion.

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People should be interested in genetic privacy because as the body of knowledge in the science of genetics grows, the problem of privacy starts to impact the broader public. Genetic privacy issues go far beyond the hotly contested subjects of social media and internet privacy, their rules, the repercussions of data breaches, and the unlawful use of personal information. Why would you want someone else to possess your genetic composition if you don't think you could sell your kidney? Do you have a say in Your DNA?

Over the years, numerous worries about genetic privacy have already surfaced. The examples that follow include some of the more significant ones. The first instance is when a genomic project starts out as modest pilot research but quickly grows beyond the creators' expectations and management capabilities. The project expands beyond the capacity of the existing resources and human capital, making it difficult to protect, coordinate, and manage.

Consent is given to a cause or a specific company (with a certain vision, team, and trust). If DNA ownership is up to the individual, they can choose to collaborate with scientists from either research or pharma institutions. On the other hand, if a private firm owns genetic data, the company has complete control over what happens to it.

Depending on the type of genetic sequencing performed, such as whether the whole genome is sequenced, in which case it identifies all sequences of a genome and provides a "big picture," a more thorough assessment of the DNA, or a micro-array sequencing, which identifies only pre-defined sequences of the DNA and as a result provides less granular information about DNA, the results of genetic sequencing can influence treatment decisions. The first scenario might lead to a better diagnosis because many diseases are caused by multiple genes, whereas the second scenario might produce uncertainty and perhaps harmful health decisions or actions.

Numerous more circumstances include genetic testing of identical twins, genetically based employment and health insurance discrimination, and more.

On the other hand, perhaps we shouldn't focus too much on genetic privacy since, considering certain serious risks to mankind, it is of little importance.
In case the human species was ever in danger of extinction due to a natural calamity or a nuclear cloud and radiation damaging DNA, perhaps we should gather, exchange publicly, and make genomes as readily available as possible. Perhaps one day a Noa's Ark of genomes (the healthy genetic sequences gathered today) will serve as a guide of what a healthy person used to be made of.
Instead, without too much concern for ownership or privacy, we should all cheerfully and actively engage in the acquisition of such genetic data.

When one considers the possibility of healthy humans vanishing off the face of the world, a private firm that earns money off our DNA or a crook who takes our personal information seems like insignificant crimes.

Here are a few suggested legislative changes that could facilitate safer future decision-making using genetic information for both individuals and businesses.

First and foremost, spread awareness among the public about DNA ownership, privacy, and the repercussions of disclosing your genetic information to vast databases controlled by for-profit corporations. From the time kids start school until they reach maturity, a fundamental, elementary genetic privacy education should be offered. It is optional but advised to involve medical experts, genetic counselors, and any other readily accessible ways.

Insist on the value of transparency. Make it mandatory for DNA data owners to communicate with you in a way that is as transparent as possible about how they are handling, storing, and using your data. Mandate that businesses make it possible for customers to withdraw their data at any time and without cause.

Change the incentives, if necessary, to discourage the sector from making money off the sale of your genetic information to companies like pharma or Ancestry. Between healthy volunteers and ill patients with hereditary disorders, a sharp line can be drawn. People that represent a healthy population and are only personally curious about their genomic data tend to adapt to direct-to-consumer DNA sequencing offers. These direct-to-consumer services only sequence a limited set of genes, and the sequencing process itself does not produce a large profit for the business. Due to this, the direct-to-consumer business will amass enormous datasets, obtain client authorization, and market clients' genetic data to a third party for a higher profit.

As technology advances and the cost of sequencing a single genome drop, enterprises will be able to make money. As a result, the service of gene sequencing might be repeated numerous times throughout a person's lifetime, collecting changes in the composition of the genome with aging (disease flare-ups, epigenetics, telomeres shortening, cancer advancement). Considering the abundance of DNA sequences, such a result might lessen the incentive to share massive databases at a price.

Do not let private corporations collect too much information about a single person.
Instead of obtaining information from whole genome sequencing, merely allow gene panels relating to the specific feature, such as pharmacogenomics- metabolism of drugs, heart disease, Alzheimer's, and so on.

Furthermore, questionnaire surveys based on additional medical and lifestyle data, in addition to genome sequencing, should not make it easier to identify a person. No one business must have a monopoly over a sizable population.

Integrate resiliency to data storage strategies as gene sequencing technology gets faster and less expensive. Regularly update informed and evidence-based practices to keep up with the evolving healthcare environment.