

I'm more afraid of my kids' genomic data NOT being sequenced than how it might be misused

My enthusiasm about human genomics and the burgeoning new world of precision medicine is usually difficult to contain. I can't help but broach it whenever healthcare or disease comes up in conversation.

"Genomic data is powerful," I exclaim. "Some day all Americans will have their entire genomes sequenced at or before birth!" I excitedly gush, "Our kids may very well end up with their genomes on a jump drive!!"

This eagerness is often shared by my friends and family, and curiosity fosters wonderful conversations. Yet on occasion, one concern supersedes the optimism of the potential of the field. "I don't want the government to have access to my family's DNA data!" This is often followed by the notion that the government will use this data in surreptitious ways.

A high level understanding of genomics might help appease these fears

Proteins are the most basic functional components of living things. Proteins serve all purposes from structure, immunity, metabolic, nutritive, enzymatic functions, and more. Everything your body is and does is achieved through the actions of these proteins. They are macromolecules comprised of amino acid chains (polypeptides.) The sequence of amino acids in any protein determines its 3D structures, which in turn abet its function. Much in the same way a hammer's shape and material composition gives it a hammering utility while the shape of a whisk allows the beating of eggs, certain proteins comprise structural elements of connective tissue, while others aid in the transport of nutrients throughout the body.

The amino acid sequence is determined by codons, each codon coded for by 3 adjacent nucleotides (any permutation of three of A,C,T, and G, each letter representing a different organic molecule.) One human genome, which is the entirety of genetic information replicated in each and every cell in an individual, is comprised of 3 billion nucleotide bases (3 billion characters of A,C,T, and G.) This is an abridged explanation; see [here](#) and [here](#) for good primers.

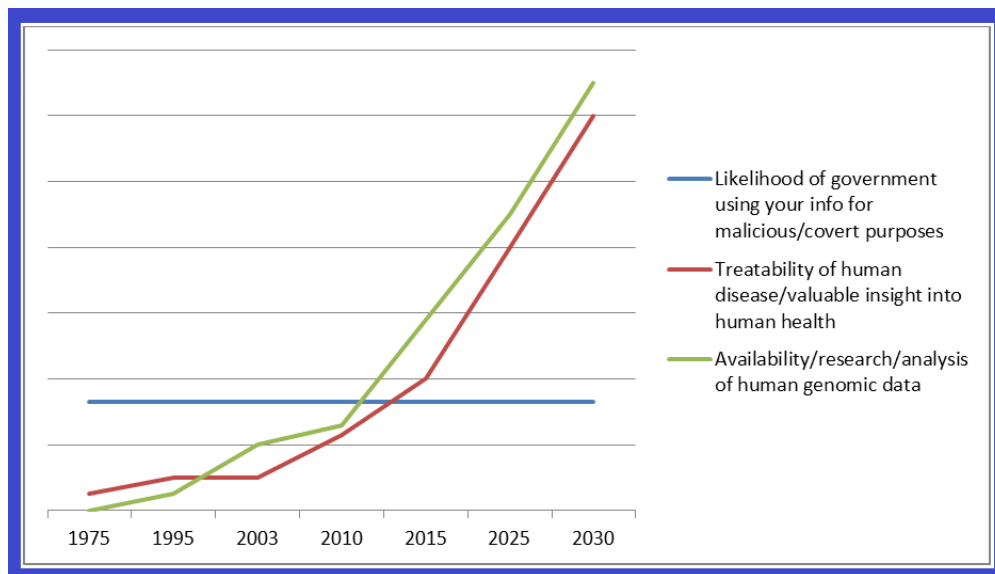
During the [Human Genome Project](#), started in 1990, it took about 10 years and 2-3 billion dollars to sequence a single human genome. Now the newest NGS (Next Generation Sequencing) machines can [do the same](#) for a few thousand dollars and in about a day, depending on coverage and other specifics. Basically, researchers can take a human tissue sample, or tissue samples from large patient cohorts, and get data in the form of nucleotide sequences. Because of the ever-reducing cost and time for sequencing, there is an ever-growing abundance of data. This information can be mined for powerful insight on human variation, the causes of disease, diagnostics, treatment, and preventive measures.

From the past and into today, disease is mainly treated based on phenotype, or observable traits in an individual. However, genotype (information contained within the genome) contains information that is unknowable by observation, including how one will respond to medications, predisposition to disease, information on mutations leading to cancer, and more.

I say “appease,” because the fears are valid

In the era of surveillance and phone tapping, I can see why one would fear misuse of genomic data. Undoubtedly, this concern is only natural. The field of genomics based on NGS data is still in its infancy. Even the experts in the scientific and medical realms do not know what lies beyond the horizon. Like any revolutionary technology, there is a reasonable expectation for responsible regulation. One example of such regulation is the Genetic Information Nondiscrimination Act (GINA) passed in 2008. This law protects individuals from discrimination based on genetic information by health insurance companies and employers. [This](#) is an excellent resource on GINA. In addition, dnapolicy.org is an organization that helps shape policy relevant to genetic issues. Their website has a comprehensive and ongoing newsfeed on the latest genetic policy news from 2003 to the present.

Simultaneously, the fears represent paranoia based on lack of scientific literacy



A decidedly unscientific and satirical chart

I don't think I'm the first to break this news, folks, but the government already has access to your data. Even before the human genome project, there have been records on all of our health backgrounds and demographics. Guess what? Your online activities are tracked as well, but I digress. Genetic data are just more info to add to the stack.

Like with GMO technology, for some reason technology related to DNA and genetics seems to frighten people disproportionately. I don't understand physics much beyond what I learned in my 11th grade “Math Physics” class. Yet I trust CERN's research on dark matter, although the Large Hadron Collider is as daunting to me as it is awesome. Is it just me, or are people more scared of technologies related to genetics, genomics, bioinformatics, and molecular biology than other scientific fields?

Nonetheless, I'm no stranger to fear. I'm far more afraid of my kids' genomic data NOT being sequenced and available than what the government might do with it. After all, the most actionable disease insights

cannot be gleaned without it. If any of my family members have severe illness in their future, I want treatment to be based on insights from their and the entire population's genomic data. Without this information, the most efficacious treatments and even cures for diabetes, cancer, Alzheimer's, and other diseases WILL NOT HAPPEN. For this reason, it will be our and our children's obligation to provide our genomic information to the greater good. When the time comes, it will be our civic duty to allow our own and our children's genomes to be sequenced, analogous to healthy individuals being vaccinated to sustain herd immunity. Furthermore, this is the inevitable future of medicine. There is no avoiding it. Everyone might as well get on the genomic medicine ship.

Like any revolutionary technology, there is a balance that needs to be maintained, a tightrope between paranoia and progress. As Thomas Jefferson said, *"Our laws and institutions must go hand in hand with the progress of the human mind."* Let's do our best to be informed and perhaps even help shape public policy, rather than recoiling in dread from a field that, like any other, has equally great potential for good and evil.

Kavin Senapathy is a contributor at Genetic Literacy Project and other sites. She works for a genomics/bioinformatics R&D in Madison, WI. She is not a scientist, but loves all things genetics, genomics, and bioinformatics. Her interests span the human and agricultural realms. Opinions expressed are her own and do not reflect her employer. Follow Kavin on twitter [@ksenapathy](#) and [Google +](#)

Read the original story at Grounded Parents: [I want YOU! \(and Your kids' DNA\): On precision medicine & fear](#)