

# Danger: Sharing Gene Data

California recently followed New York's lead in attempting to curb the growth of direct-to-consumer genetic testing, which offers people analysis of their

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genes that could predict their risk of contracting a serious disease or reveal other potential health issues.

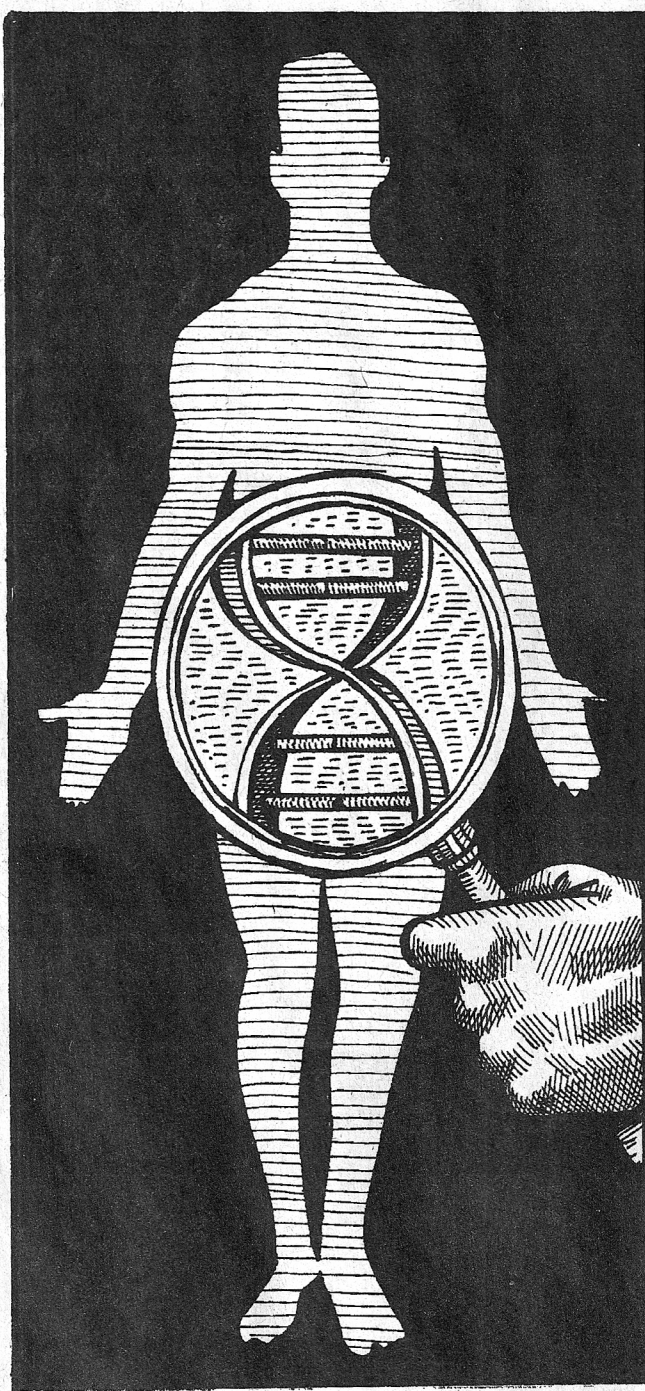
Citing the lack of doctor involvement and concerns over laboratory licensing, California threatened civil and criminal sanctions for non-compliance with regulations. Although conforming to state law may assuage the Department of Health, personal genomics companies create significant and unforeseen privacy issues that cannot be remedied by simple compliance.

Personal genomics refers to the exploration of entire individual genomes and the genotyping of discrete DNA sequence variations that potentially correlate with diseases and character traits. Although there are more than 1,000 individual genetic tests available, plummeting costs have made whole genome sequencing a marketable consumer technology, albeit lacking significant federal Food and Drug Administration oversight.

Personal genomics companies are typically health or recreationally minded, either giving customers limited access to vetted gene-disease relationships or giving them full access to all their raw genomic information, with ways to share and compare it with others.

In contrast to medical records that are traded almost exclusively among authorized doctors, personal genomics will reveal equally if not more revealing information to be viewed, traded and potentially even data-mined in the online bazaar. Similar to the devastating erosion of online privacy where effectively indelible Web pages disclose personal information, confidential e-mails are rapidly and widely circulated, and surfers unwittingly drop revealing digital bread crumbs, personal genomics undercuts medical privacy to a new degree.

And, like many users on social networking sites, people may not realize how much of their privacy is compromised.



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Unlike many Web neophytes who casually and cavalierly post their entire lives online, sharing personal genomics will not only have privacy repercussions for individuals, but also for their relatives. A person's genome reveals half of the genome of his parents and children, and a substantial fraction of his siblings'.

Every human is inextricably linked with the DNA that describes not only his past but also foretells his medical future. Your DNA identifies you perfectly and absolutely. Not even twins share their entire 6 billion base-pair lengths of diploid DNA. Although we do not currently understand even a subset of the genetic influences

on our lives, eventually we will; but by that time it will be too late to retract the genomic data that many of us imprudently uploaded.

Notwithstanding the repercussions that will most likely occur despite the best intentions of Congress to fight genetic discrimination, placing high barriers to acquisition of genomic data may chill the use of personal genomics and the concomitant important collection of data. Individuals should be free to share their own genomes, and the government does not have a strong enough interest to constrain consumers' free speech. But without substantial oversight, personal genomic companies might be unable to effectively deal with the varied ethical and moral concerns that might arise, and consumers will belatedly realize the devastating privacy implications for themselves and their families.

Like the Internet, personal genomics will require society to re-evaluate our current standards of confidentiality and privacy. Personal genomics companies might consider a requirement for an extensive live consultation with a genetic counselor and a second tier of informed consent before allowing consumers to share their results.

A comprehensive, lay-friendly and scientifically reliable database that explains which genetic information is useful medically and revealing about a person's intimate health history would also help to clarify the need for privacy in personal genomics.

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