

Google Wants to Track Your Medical History —And Your Genome

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IN a recent review of 23 internet companies by a consumer watchdog group, Privacy International, Google was the only one to receive the lowest grade, reserved for those with “comprehensive consumer surveillance and entrenched hostility to privacy.”

With that low mark in mind, you might find the idea of Google’s having its virtual hands on your medical history a bit disturbing. The company, and its rival Microsoft, are each taking the first steps toward the burgeoning, and lucrative, industry of electronic health-records management.

Having your medical records in an accessible, searchable and consistent format is certainly appealing. But you, and your doctor, would also become a magnet for advertisers offering services based on your particular medical history.

Eminent technology investor and pundit Esther Dyson isn’t worried about privacy policies, her personal records being hacked, or these companies cooperating with the National Security Agency. In fact, she wants you to turn over not just your medical records, but your personal genetic sequence as well.

In a recent interview on Charlie Rose, Dyson explained that she’s among ten people about to put their health histories and genetic sequences on the internet for public viewing. She optimistically predicts that lots of us will soon entrust such informa-

tion to online companies, albeit in private accounts.

Although Dyson acknowledged some of the troubling questions this prospect raises, she quickly dismissed them: “Like it or not, it’s gonna happen.”

Her rhetorical dodge is unfortunate. The convergence of biotechnology, the web, and big business is, in fact, quite alarming.

Here’s the scenario: After signing up online, you receive a kit in the mail. In your home, you provide a saliva sample in the supplied cup and ship it off to a lab. For a few hundred dollars, much of your genome is sequenced, and the company places it on a website. It’s then linked to your complete medical history, also online.

At this point, the company says, you can learn about your predispositions to diseases, conditions for which you carry a recessive gene, and genealogical information. The website offers medical advice, along with advertisements for potentially useful products and services. You can even communicate with people with similar genetic characteristics, making “friends” and forming “groups.”

That seems to be the plan of a Silicon Valley start-up, 23andMe, named for the 23 pairs of chromosomes that hold your genome. Google, Genentech, and venture capital firms have invested at least \$10 million in 23andMe. Its founder recently

married one of Google's founders. Ms. Dyson is also an investor and board member—something that didn't come up during her interview.

The cost of genetic sequencing is rapidly falling. Though a complete sequence still goes for about a hundred thousand dollars, federal grants—and even a privately backed \$10 million prize—are pushing down the cost. Some analysts believe that a complete genome will be sequenced for just a thousand dollars in five years. For now, 23andMe would rely just on key segments of your genome. Its service should launch within a year.

First, important private information will move outside of your control. If divulged, your genome and medical history can impact critical decisions by prospective employers, insurers and even spouses. Are you ready to entrust this deeply personal information to a company that gets an "F" in privacy?

Second, this data will be a goldmine, but only the corporations will get a cut. Researchers currently spend millions trying to discover genes that correlate with medical conditions. With thousands of genomes and health records to compile and compare, 23andMe's technicians and statisticians will be in a position to

compete with more traditional researchers. The genetic correlations they uncover will be patented, and remedies for associated ailments sold at a premium.

For example, the test for genes related to breast cancer costs \$3,000—instead of a few hundred—largely due to patents held by Myriad Genetics, a biotech company founded by a publicly funded researcher.

Will you get a share of the patents, and profits, on genes discovered by this service? You relinquished any claim when you clicked "I accept" to a long, and generally unread, term of agreement.

Finally, the exact implications and potential inaccuracies of what we may learn are likely to be lost. How might you or I react upon discovering that we have the gene for a fatal, untreatable condition? How will the company make it clear that such a gene may be merely a tendency to develop the disease? What if a father learns that he is not genetically related to his child? What if these results are inaccurate?

Such profound discoveries can be difficult to process in isolation from a broader medical context and counseling resources, a challenge that we are

already confronting with the rise of at-home genetic tests.

23andMe plans to offer recommendations to help form social groups based on the aggregated information of thousands of users. This "Web 2.0" model has worked well for Amazon and MySpace. But in its race to transform the falling price of genetic sequencing into a dubious consumer product, the company fails to realize that your medical history and personal genome are fundamentally different than your reading habits, and "patients" are not synonymous with "consumers."

In the end, the underlying view of Google and 23andMe doesn't depart significantly from traditional Silicon Valley culture: that we can depend on technology to solve the world's social problems. But given Google's privacy record, Big Biotech's aggressive patenting of the human genome, and the importance of our medical and genetic information, we should think twice about transferring this model to health care. Contrary to Dyson's claim, this future is not inevitable.

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