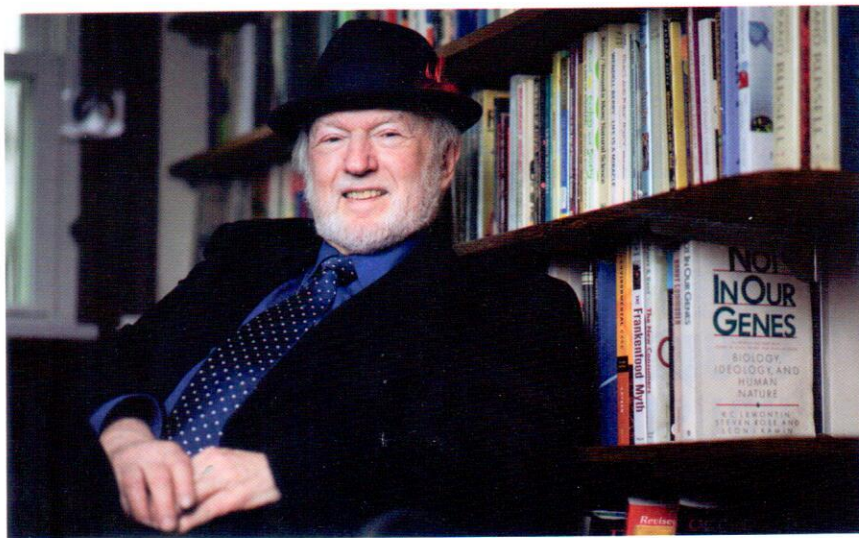


# Taking a Closer Look at DNA Ancestry Kits

Just how accurate—and private—is genetic testing? We asked a Tufts expert. **BY GENEVIEVE RAJEWSKI**



**G**enetics tests like 23andMe are all the rage. You just send in a saliva sample and you can find out where in the world your DNA hails from. A thrilling prospect, to be sure, but what happens with your genetic information and material after you've received your results? Does it get sold to the highest bidder? Used for research? Something else? To find out, I spoke with Sheldon Krimsky, the Lenore Stern Professor of Humanities and Social Sciences and an adjunct professor in public health and community medicine at Tufts.

## What are the privacy issues?

The companies offering these tests largely make their money not from doing the tests, but from selling the genetic information to other companies interested in having access to large genetic databases. Almost 50 percent of the firms that sell you your ancestry information turn around and sell your genetic information to some other company. Often these are pharmaceutical

companies trying to understand how variations in certain sections of the human genome may be useful in drug development. Only about 10 percent of the companies that offer ancestry tests destroy your original sample. The vast majority hold onto your sample or sell it. It's not just the data, but your actual genome, that's being shopped around.

## There must be privacy policies, though?

First, privacy policies vary from

company to company. Reading the small print can be illuminating. Second, the companies offering testing services often go up for sale, and their privacy policies typically indicate that they bear no responsibility for your privacy once the company is sold—anything you signed is not reliable anymore. In effect, *you* need to keep in contact with the company and keep yourself up to date on its policy. How many people are going to do that?

## I've heard that the records of the samples don't include names.

Even though your name is not listed on the database, when the data is sold to somebody, the records can be de-anonymized. It has happened before—people have been able to take genetic information with no name on it and, through other databases, find the name associated with that genetic material.

## How accurate are the tests?

We don't really know, because the companies selling these services—and there are close to forty of them—don't share their data, and their methods are not validated by an independent group of scientists, and there are not agreed-upon standards of accuracy. People have sent their DNA to several of these companies and found differences in the results—though not necessarily radical differences. So you have to look at the percentages you receive back with skepticism.

## Why do they return different results?

Each company offering these services uses its own proprietary database of DNA samples called ancestry informative markers (AIMs) from current populations in Asia, Africa, Europe, and the Americas. From within those databases, they each select for a certain number of alleles—one member of a pair of genes located at a specific position on a specific chromosome—and in these spots, use the genetic variations known as single nucleotide polymorphisms (SNPs) as the basis for

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