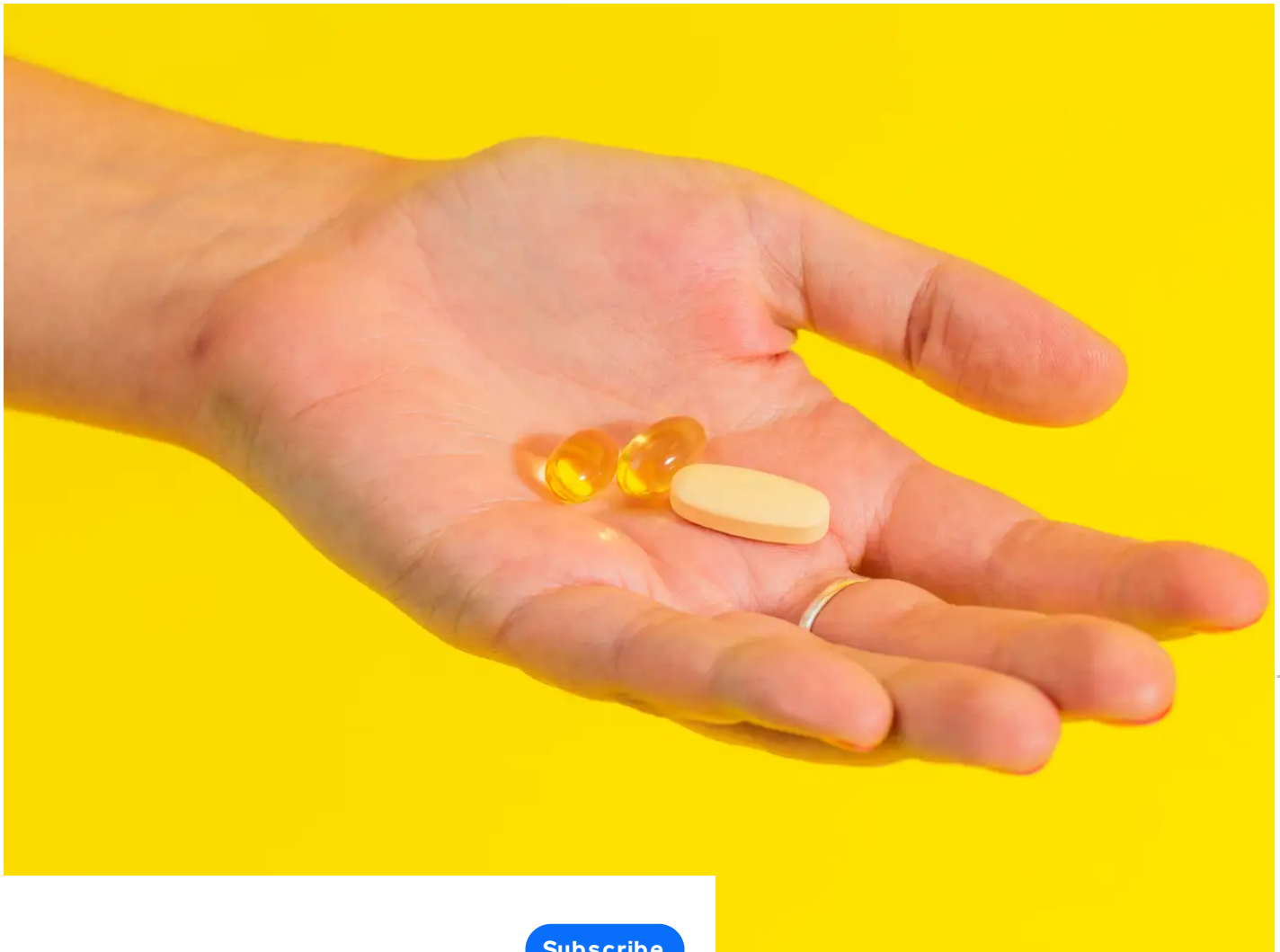


[HOME](#) > [SCIENCE](#)

DNA-testing companies like 23andMe sell your genetic data to drugmakers and other Silicon Valley startups

Erin Brodwin Aug 3, 2018, 11:45 AM ET

[Download the app](#)[Subscribe](#)



anonymized genetic data with pharmaceutical giant GlaxoSmithKline as part of a \$300-million deal.

- **Some companies like 23andMe have a history of selling customer DNA data with what they call "third parties."**
- **Ancestry, another genetics-testing company, had a partnership with Google's life-extension spinoff Calico.**
- **Here are the other for-profit companies with which gene-testing startups have sold your data.**

Perhaps you didn't intend for that spit sample you shipped off to be used for research on antacids. But that could be what happens with the data that some genetics-testing companies like Ancestry, 23andMe, and Helix have collected from billions of customers and stored in their databases.

Both Ancestry and 23andMe have a history of sharing anonymized consumer data with private companies, also known as "third parties." Last week, 23andMe took that policy to a new level when it announced a plan to share the genetic data of millions of consumers with pharmaceutical giant GlaxoSmithKline to help the company develop new drugs.

f other drug companies and with
r behind Pantene shampoo and

the antacid Pepto-Bismol.



Here are the private companies that the biggest genetics-testing companies share data with



Glassdoor

Apart from its partnership with GlaxoSmithKline, 23andMe has active partnerships with at least four other large pharmaceutical companies:

AbbVie, Bristol-Myers Squibb, Regeneron, and Genentech.

Subscribe



In addition to these private partners, 23andMe shares its data with several public academic institutions and nonprofit research groups like the University of Chicago.

Ancestry, which maintains a 5-million-person consumer database of genetic information, once partnered with Google's stealthy life-extension spinoff Calico to study aging. But a company spokesperson told Business Insider that Ancestry is currently only partnered with universities and research institutions. These include the University of Utah and the American Society of Human Genetics.

Helix has active partnerships with about 25 companies, according to Justin Kao, Helix's co-founder and senior vice president of business development. Kao told Business Insider that the list includes at-home lab testing startup EverlyWell and healthcare provider Geisinger Health.

But unlike Ancestry or 23andMe, which have shared the data of millions of anonymized customers with private companies, Helix does so only when the user consents via one of those company partners. EverlyWell, for example, uses Helix's technology to offer customers at-home DNA tests for food sensitivity and metabolism, while National Geographic uses Helix for its genealogy tests. Those companies may prompt a user to opt into research that they are doing, and only then would their data be shared.

Subscribe

ies share your data with

third parties



Hollis Johnson

A big reason many genetics-testing companies share data with third parties is for research. Scientists want to learn more about the genetic roots of various conditions and diseases in the hope that this information will lead to better treatments or even cures. Both nonprofit academic institutions and drug companies are doing this kind of work.

"We all have some disease or health issue that we care about. 23andMe has created a research platform to enable interested customers to participate . . . appear, but for people to come

Subscribe

3andMe CEO Anne Wojcicki



The average customer who chooses to let 23andMe share their data for research contributes to more than 230 studies on topics including asthma, lupus, and Parkinson's disease, the company says.

Similarly, Ancestry's partnership with Google's Calico was aimed at studying the genetics of longevity, though neither company has yet published any research that resulted from the collaboration.

How to choose what data you share — or delete it altogether

When you register your spit sample with Ancestry, 23andMe, or Helix, you're offered choices about whether you want to share your data, when, and with whom. However, privacy advocates have pointed out that these options can often be confusing.

Plus, when asking customers whether they agree to share their data with third parties, Ancestry, 23andMe, and Helix all use different language to describe the choices and present the option at a different stages in the sign-up process. That can make wiping your data from any of those platforms difficult and time-consuming.

Subscribe

pen, such incidents could allow
os without your knowledge.



initially signed up.

Through 23andMe's 4-year partnership with GSK, for example, GSK gets anonymized summaries of data from customers who've opted to share their data for research. Privacy advocates find that vexing because the data of existing customers who may have previously opted into sharing their data could now be included as part of the larger base of data shared with GSK.

"The very setup of this venture suggests that its initiators are not quite serious about 23andMe's customers' informed consent," Udo Schuklenk, a professor of bioethics at Queen's University, told Business Insider via email.

It's not easy to delete your information from some genetics-testing platforms after you've signed up. (If you want to delete your genetic data from one of these sites, check out our guide). If you've opted to share your data for research, 23andMe could keep your physical spit sample — and the genetic data gleaned from it — for up to a decade.

NOW WATCH: Popular Videos from Insider Inc.

Subscribe