

QUARTZ MEMBERSHIP



How businesses are building an industry using your DNA

Member exclusive by



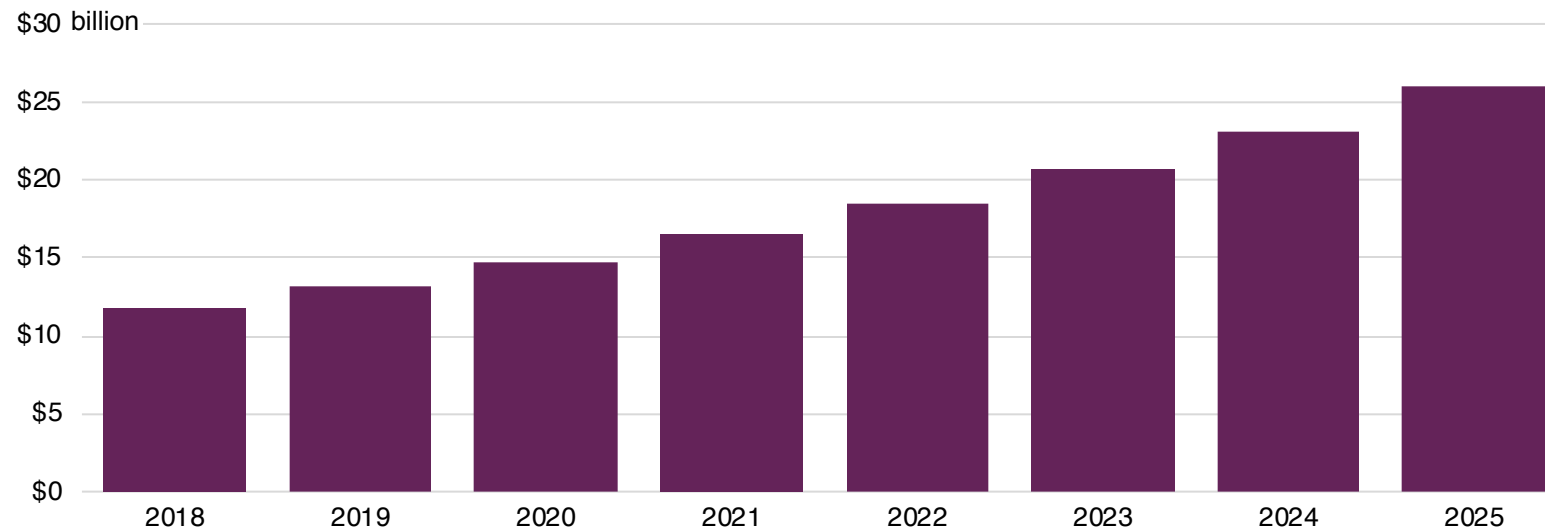
Dasia Moore

The business of genetics

When scientists first finished sequencing a human genome in 2003, the hope was that medical knowledge would soon become deeper and more personalized. Since then, DNA science has certainly changed medicine. It has also created a new type of business: direct-to-consumer (DTC) genetic testing. Now, just as consumers are becoming more leery of at-home genetic testing kits, the business of DNA is to expanding to new frontiers—and further blurring the boundaries between doctor's office, startup, research lab, and law enforcement.

Global genetic testing market

Including DTC and other testing. Global Market Insights projections for 2019-2025 based on actual 2018 market size and projected compound annual growth rate of 11.9%.



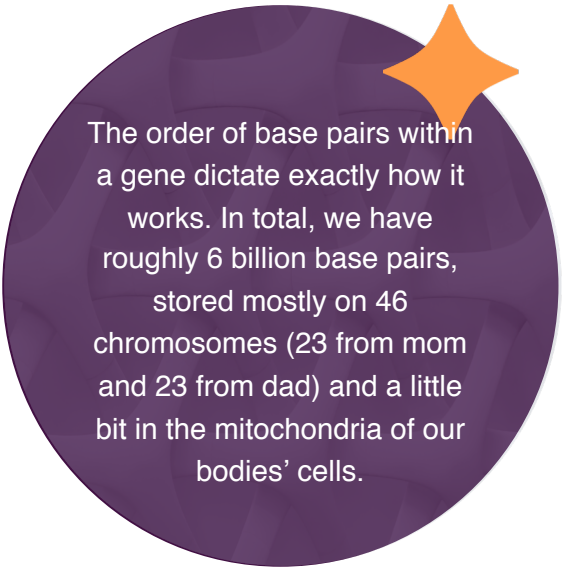
DNA 101

A quick refresher on how DNA works, courtesy of Quartz's Katherine Ellen Foley:

- If your body were a house, your **genome** would be the architectural blueprint. Instead of drawings, though, our genome is made of **DNA**.
- Each DNA protein has an opposite mate to give it the appearance of a tiny, twisted biological ladder. These coupled proteins make up **base pairs**.
- Hundreds to millions of base pairs make up a **single gene**, which scientists call the “functional unit of heredity” because they each have a job (though many of those jobs are still unknown).

The ability to sequence entire genomes (or look at the whole blueprint) is important for doctors and researchers seeking to understand a person's entire health profile. To keep costs down and deliver fast—if inconclusive—answers, DTC DNA companies stop short of the blueprint and just look at a few details in a few key rooms.

- Analysis of **mitochondrial DNA** (mtDNA) passed down directly from mothers and **Y-chromosome DNA** passed down directly from fathers is key to ancestry testing.
- **Genotyping**, or looking for specific mutations on specific genes, is one of the most common types of genetic testing today and can reveal some ancestry and health information.



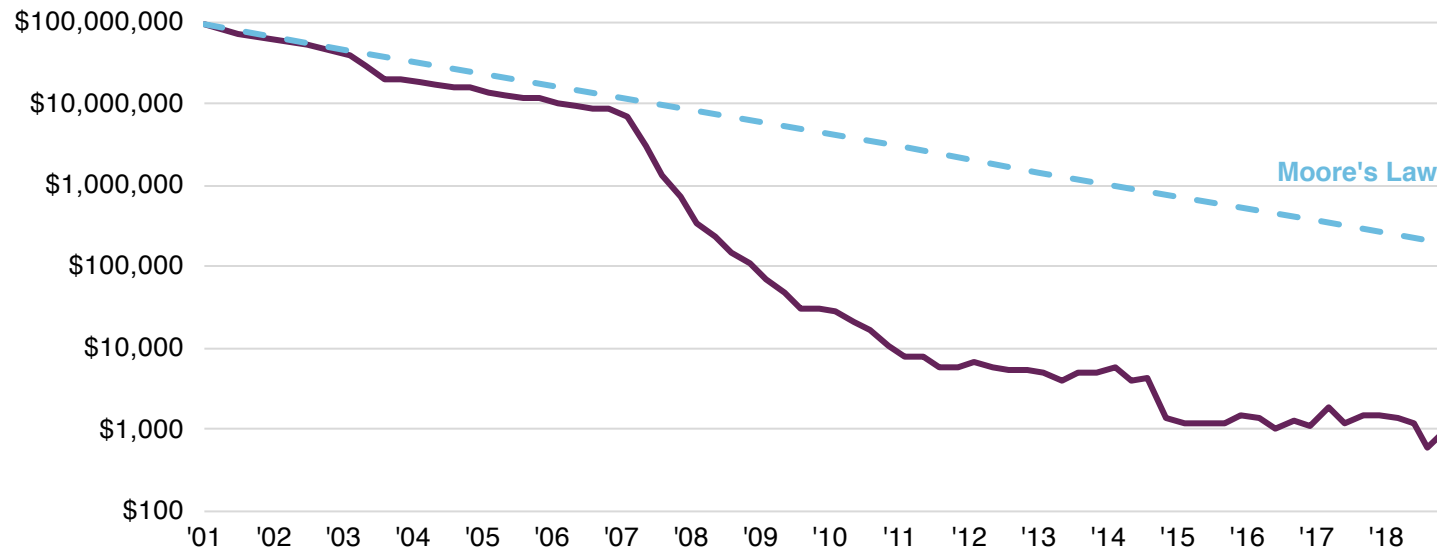
The order of base pairs within a gene dictate exactly how it works. In total, we have roughly 6 billion base pairs, stored mostly on 46 chromosomes (23 from mom and 23 from dad) and a little bit in the mitochondria of our bodies' cells.

Cost is the magic word

Cost was the most important factor in taking genetics out of the lab and into the world's mailboxes. In 2001, sequencing a human genome cost \$95 million. By 2019, that cost was down to \$942. Notably, this cost reduction has outpaced Moore's Law—the rule of thumb that computing costs will halve every two years and a general benchmark for evaluating the cost of innovative technologies over time.

The cost of sequencing a human genome had fallen rapidly

Cost per human genome. Note the log scale.

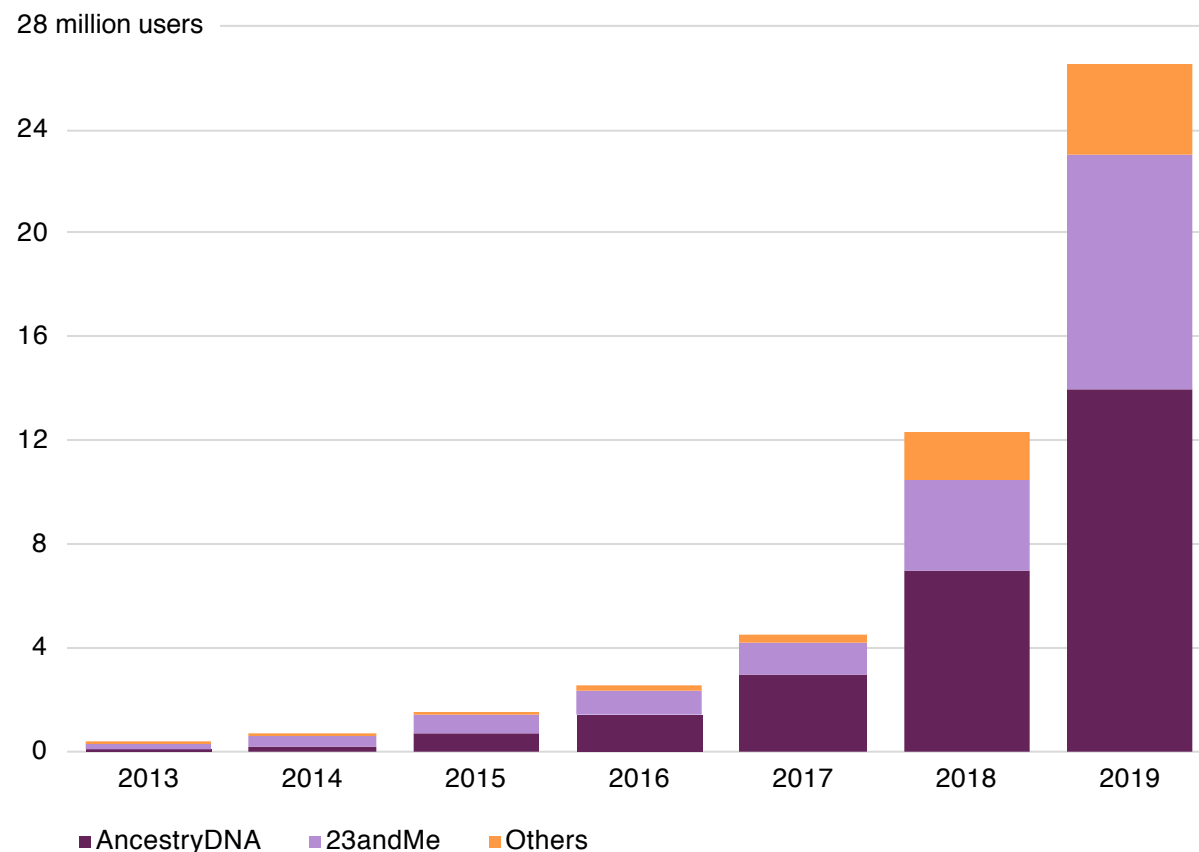


DIY DNA: The companies selling science directly to consumers

According to the International Society of Genetic Genealogy, there are 32 companies that offer genetic testing to consumers. The largest by far are AncestryDNA and 23andMe, with more than 85% of the market.

AncestryDNA emphasizes family history, giving users tools to find relatives who have also taken the test. 23andMe tests can be used for ancestry information, but they also screen for around 40 genetic mutations that lead to increased risk for breast cancer, colorectal cancer, Parkinson's disease, and more. 23andMe is the only US-based DTC DNA company allowed to provide this information to consumers without a licensed genetic counselor.

AncestryDNA and 23andMe dominate US at-home DNA testing
Users for the leading US-based DNA databases, through Jan. 2019.



Have we reached the end of the DNA boom already?

23andMe started 2020 with a layoff of 14% of its staff. AncestryDNA followed, laying off of 6% of its staff. How did this happen in an industry that was booming just months earlier? Part of the contraction could be explained by simple market saturation: Six years into the DTC DNA boom, prospective new customers are few and far between, and existing customers have no reason to make a second purchase. But slowing growth could also arise from consumer doubts about how much at-home kits can actually tell them—and concerns about DNA privacy.

43%

of US adults aged 35 and younger say they have considered getting a genetic test

4-6 million

MIT Technology Review's estimate for 2019 consumer test sales, compared to about 13 million for 2018

47%

of US adults who took a DNA test or had a family member do so say they are concerned about privacy

What consumers want vs. what consumers get

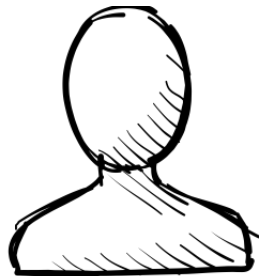
Consumers take genetic tests in hopes of getting more information about one of two things: their health or their ancestry. Theoretically, DNA could tell us a lot about both of those things. But in practice, DTC testing falls short.

What you might be looking for	Can DNA testing tell you? Why or why not?
Matrilineal or patrilineal ancestors	Yes. Matrilineal lineage can be traced using mtDNA, which is passed down through mothers. Y-chromosome DNA traces patrilineal ancestors.
Your racial or ethnic heritage	Not really. First off, race is not biological. As for regional heritage, DNA testing companies compare the mutations on your DNA with those commonly found among people who self-identify as being from a given region. This method is imprecise, and it's especially incomplete for people of color, as most companies have very limited reference data for populations that are not of European descent.
Whether you will get breast cancer, or any dominantly-inherited condition	No. On one hand, if a DNA test finds certain mutations for dominantly-inherited diseases, the results are generally accurate. But again, DTC DNA tests only look for a small number of mutations on a small number of your genes, so negative results are not conclusive. What's more, regulation blocks most DTC companies from sharing this information with consumers without having a physician involved.

Where is your DNA going?

Privacy is another domain where DNA testing can fall short of consumer expectations. The truth is, your genetic information is unlikely to stop exactly where you send it. DTC companies operate in a network that can sometimes blur the lines between the startup, the lab, and the doctor's office.

You may choose to share your DNA with resources that can help you learn more.

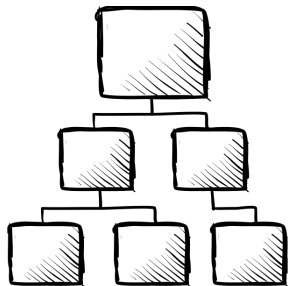


Databases that connect users to relatives based on their test results can be useful for genealogy research. These are almost always opt-in.

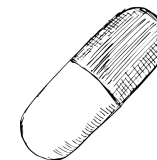


Genetic counselors can confirm or address genetic conditions. Most DNA companies are required to work with a doctor to give you health information.

But a DNA testing company could share your genetic information more widely.



Law enforcement. Some DNA companies openly partner with police to identify criminal suspects. Other companies are less transparent.



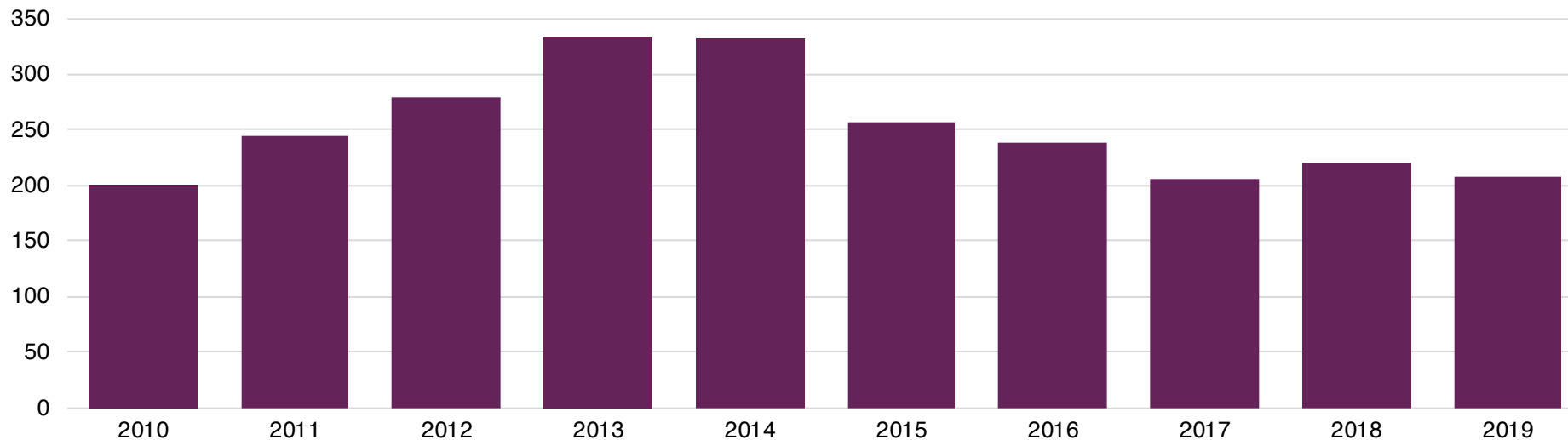
Pharmaceuticals. Some DNA testing companies raise revenue by selling patented drugs developed in-house, or by selling anonymized genetic data to pharma.

The ethics of investigating our genetic differences

Differences among humans come down to a small subset of variations on about 0.1% of our total DNA, but genetic tests can have the effect of amplifying that 0.1%. DNA testing companies' emphasis on heritage and their convention of breaking ancestry down into neat percentages runs the risk of reinforcing myths about race. They can also open the door to genetic discrimination. Though many countries ban health insurers from discriminating based on health, other institutions—including other types of insurers, schools, or housing programs—can and have excluded people after discovering their genetic testing results. Even when discrimination is explicitly banned, like under employer and insurer regulations in the US, illegal mistreatment does not necessarily go away.

In the US, there have been at least 200 genetic discrimination lawsuits annually since 2010

Based on cases filed alleging violation of the Genetic Information Privacy Act, passed in 2008.

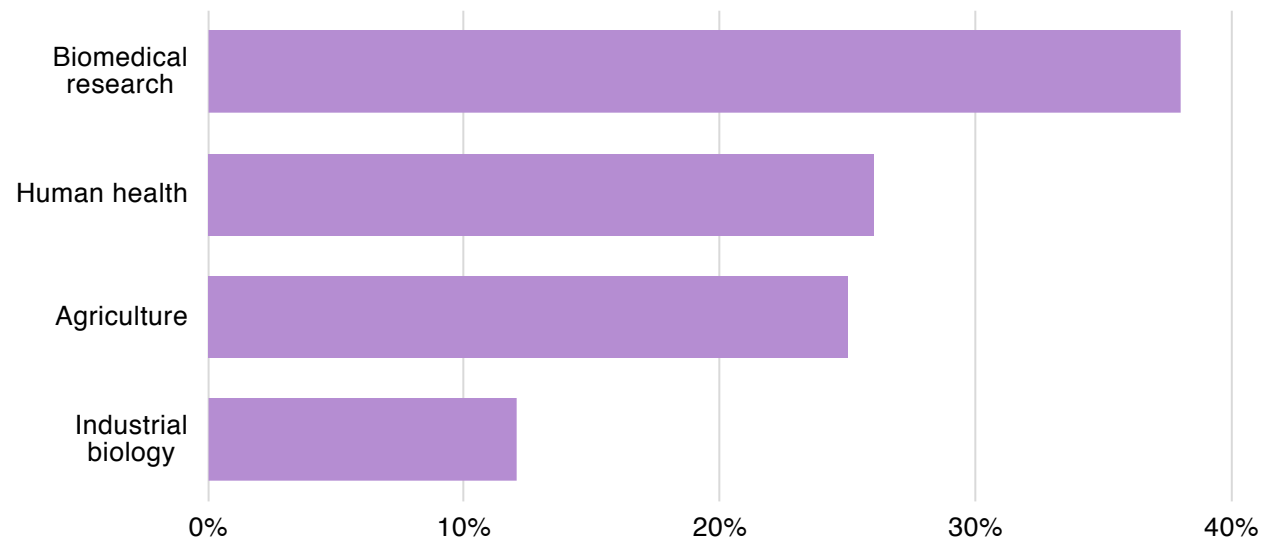


The DNA boom beyond at-home kits

Declining growth for DTC genetic testing companies does not mean the business of DNA is over. Genetic science has implications beyond our personal curiosity about our health and heritage. The aspirations sparked by the Human Genome Project—a world without genetic disease, a cure for cancer, or perfectly personalized medicine—are dreams researchers still hope to make reality. And they're looking beyond reading genes. Scientists began experimenting with editing genomes in the 1970s. Gene editing became simpler, cheaper, and more widespread following the 2012 discovery that scientists can use Crispr, a natural molecule, to alter genes or turn them on or off.

Gene-editing companies, by focus

The share of 2017 gene-editing companies focusing on each of four major applications.

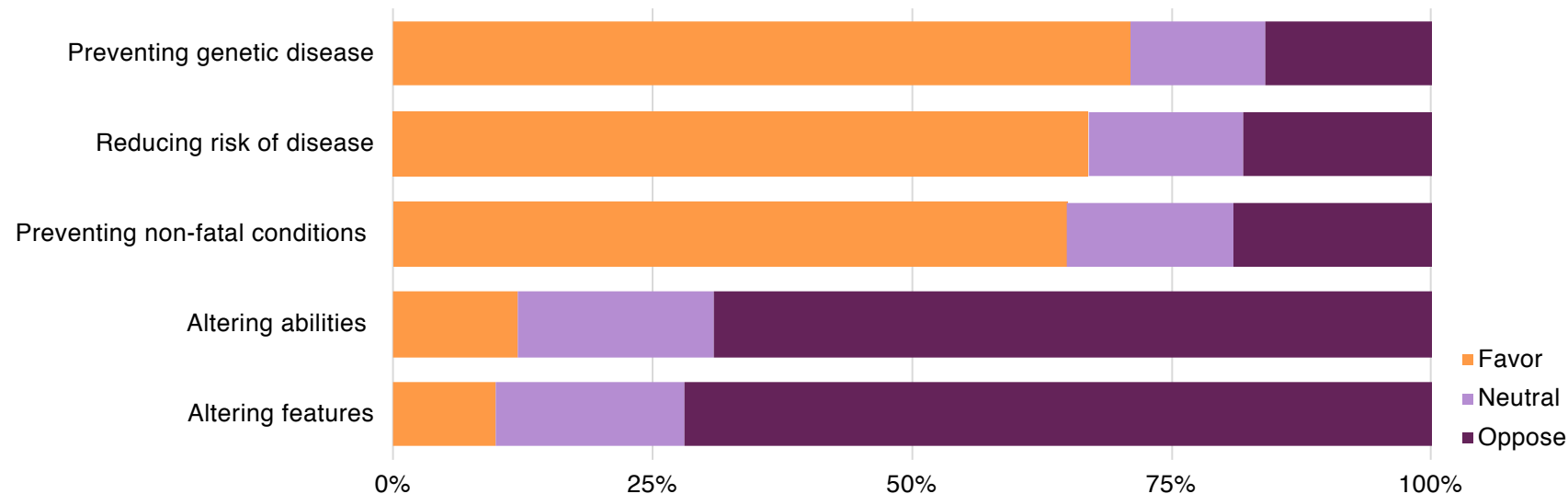


Proceed with caution

Unsurprisingly, gene editing raises all the same ethical concerns as gene reading—and then some. Ethical concerns over gene editing reached a fever pitch in 2018, when Chinese researcher He Jiankui announced the birth of twins whose genes he had edited using Crispr in order to make them HIV-resistant. A Chinese court later sentenced He to three years in prison. Designer babies are not all the public fears when it comes to gene editing. In theory, Crispr could also be used to destroy species that humans consider pests or to create bioweapons.

To the general public, only certain uses of gene editing are okay

Based on US adult responses to “When is gene editing acceptable?”

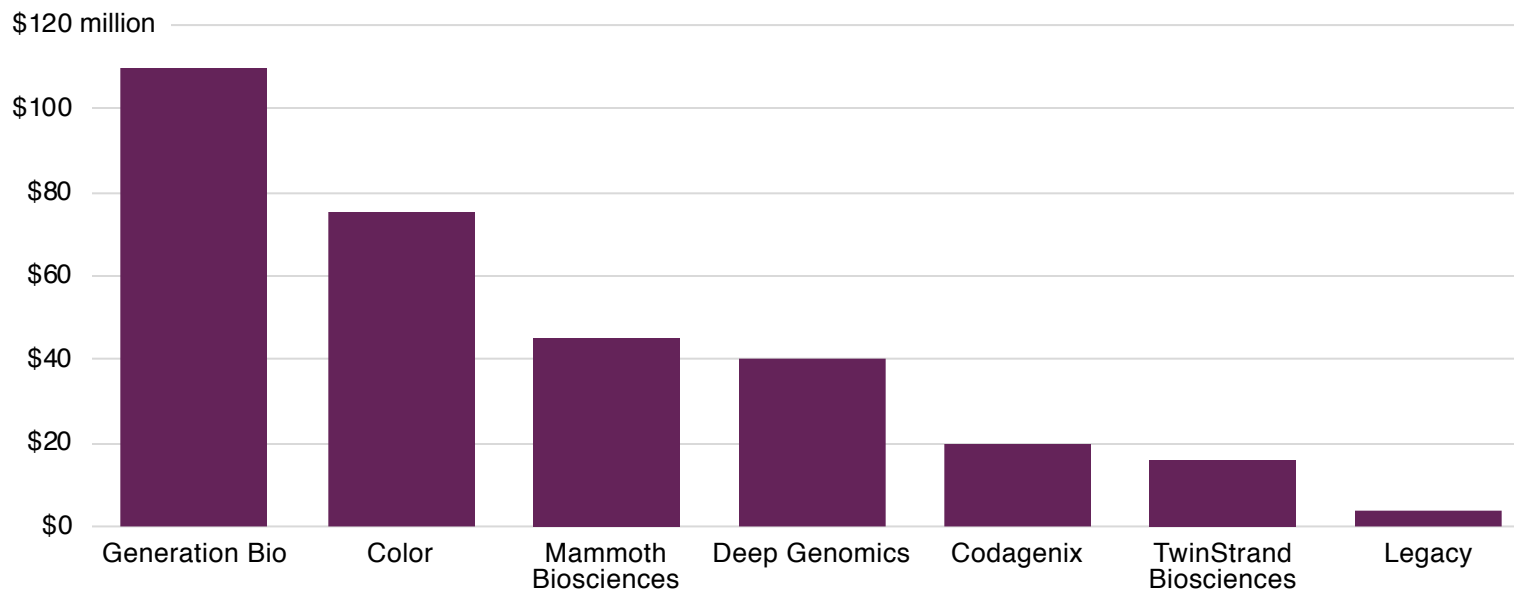


The desire to know more about DNA isn't going anywhere

Questions remain about how the growing DNA industry will be held to high standards of ethics, accuracy, and privacy. But excitement about DNA science and the industries it can create persists, too. According to Crunchbase, seed and venture capital investors have poured \$6.5 billion into genetics startups, most of it since 2003. This year, seven genetics startups have already raised a cumulative total of \$300 million in capital. Notably, five of the seven are gene therapy and gene editing companies. Just one is a gene reading business, and none are DTC.

2020 funding rounds for genetics startups

As of February 11, 2020.



Want to know more? Read coverage of DNA from Quartz health reporter Katherine Ellen Foley, who contributed to this presentation.

- [A biotech startup thinks its idea could cure dementia—but scientists have their doubts](#) – For a glimpse of the future genetics and biotech startups are hoping for.
- [Why DNA testing kits shouldn't be on your holiday shopping list](#) – If you're considering giving a genetic test as a gift.
- [10 years after the Nobel Prize, telomeres are still a murky lead in longevity research](#) – For a deep dive on the “genetic hourglasses” inside our cells.
- [Rare genetic mutations protected a woman from developing Alzheimer's](#) – In case you're wondering, not all mutations are bad!

You'll also enjoy our member-exclusive field guides, [Gene reading](#) and [Gene editing: Biology's gold rush](#).

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