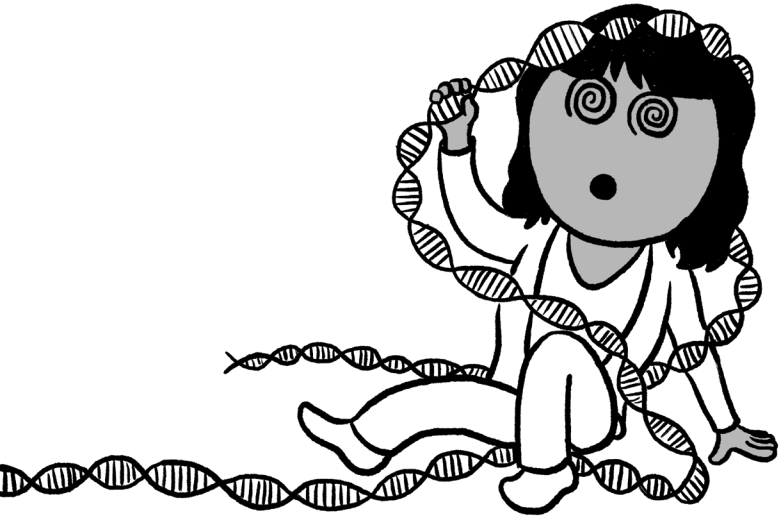
UNRAVELLING DNA

An explainer on the political and social consequences of DNA testing and databases



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Unravelling DNA: An explainer on the political and social consequences of DNA testing and databases

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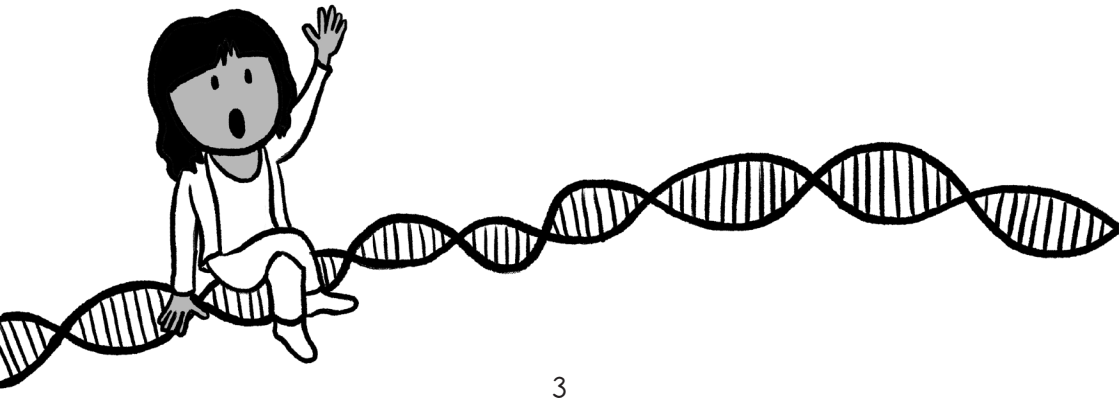
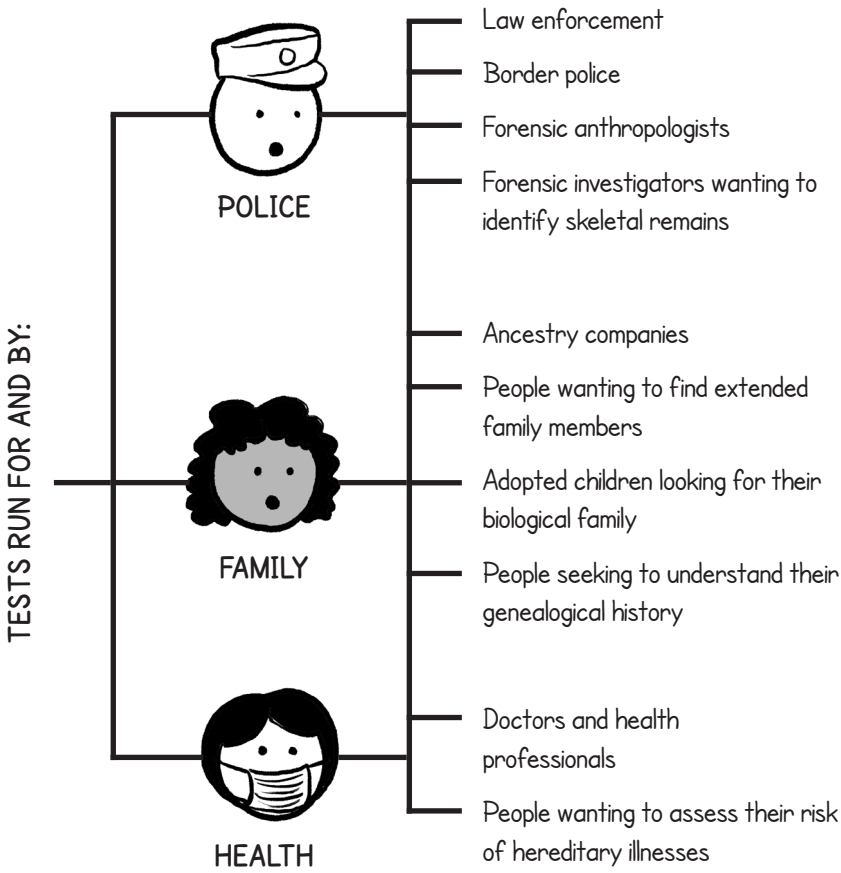
DNA is a molecule that is found inside almost every cell of every living organism. It contains the genetic code for how we reproduce, develop, and grow. It can reveal a lot - but not everything - about us!

DNA is passed down from generation to generation. We have DNA in common with biological relatives - so what they do with their DNA can affect you, and what you do with yours can affect them.

Today, using DNA to answer questions about who we are is becoming more and more widespread - by governments, companies, individuals, and more. The impact of DNA tests is multiplied thanks to the spread of digital technology, too - we can share results, build DNA databases, and be in contact with each other faster and easier.



There are lots of different types of DNA tests out there.



But DNA testing brings with it lots of new risks - and possibilities.

What can DNA tell us?

...it can hint towards what might happen as our bodies age.

Though DNA can reveal a lot about the organism it's taken from, it is just one of the factors that determine how we grow and develop

The environment and society we're in

What we eat

The type of lifestyle we lead (exercise, smoking, drinking alcohol)

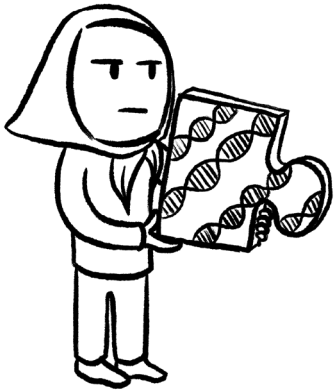
Our DNA

This is why **health predictions** based on DNA are limited in what they can reveal. A person might carry a gene that means they are at higher risk of a certain disease, but that's just part of the story.

...it can tell us who we're biologically related to

Each biological parent passes half their DNA, in big chunks called chromosomes, to their child - that usually means that biological relatives have some DNA in common with each other.

EXAMPLE



The Grandmothers of the Plaza de Mayo have been searching for their grandchildren since they were kidnapped from their parents by the Argentina military dictatorship between 1976 and 1983. As of 2021, they've used DNA sampling to identify more than 120 of their kidnapped grandchildren who were secretly adopted.

... it can be matched from a small sample to a specific person

Every person's DNA is unique from person to person, and the same in every cell of a specific body. This is what's often used by law enforcement - matching a DNA sample found at a crime scene to a DNA sample held in a database.

But all DNA tests - like with any technology - can be flawed. Human error, test accuracy, sample contamination, and other factors can lead to false matches being made. There are growing numbers of cases where people have been mistakenly convicted of serious crimes based solely on DNA evidence.

EXAMPLE

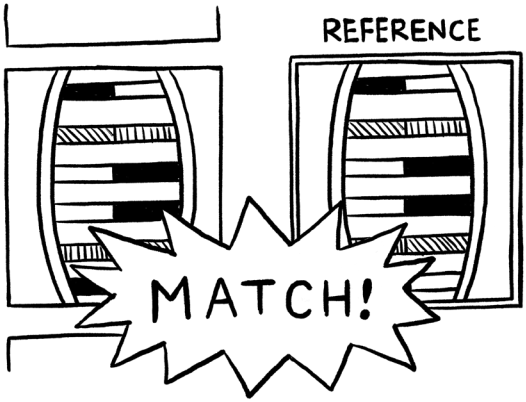
Josiah Sutton was released in 2004 after serving 4½ years of a 25-year sentence for a rape he did not commit. He was convicted based on a flawed case and faulty DNA testing - a lab technician testified that the DNA found on the victim was an exact match with Sutton, but actually, 1 in 16 Black men share that DNA profile.

...it can "trace" a person's ancestry

We all have parts of DNA that are inherited from our ancestors. But ancestry is very different to heritage - we don't inherit ancestral wisdom, or knowledge of our cultural heritage, from DNA.

Ancestry companies use databases that have "reference samples," which are DNA samples that companies use to compare a customer's DNA against in order to draw their findings. They usually have more samples from European countries, and fewer from Asia and Africa, so their results are more accurate for white populations than for Black and brown people.

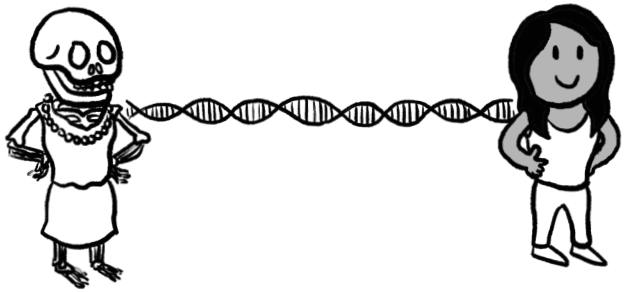
But only half a parent's DNA is passed down to the next generation, and it's just by chance which chunks of DNA are passed down - so even ancestry tests done by twins often yield completely different results!



...it can help us understand history

History as taught in mainstream education often prioritizes the stories of the colonizers instead of the colonized - those with power are the ones who decided what got documented and what got ignored. But DNA can help provide part of an alternative story. DNA researchers working to "decolonize DNA" have made use of ancient DNA, known as aDNA, to reveal alternative histories that challenge colonial narratives by combining genetic results with oral histories, anthropological evidence, and more.

EXAMPLE

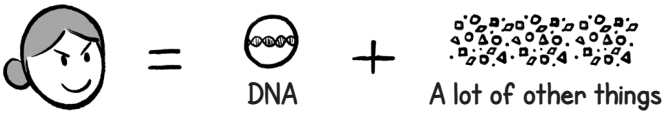


Dr. Maria Nieves-Colón, an anthropological geneticist who grew up in Puerto Rico, has used aDNA to connect precolonial, Indigenous populations from Puerto Rico with modern-day Puerto Ricans. This sits in opposition to the narrative of Indigenous extinction that is commonly taught today.

What are the problems with DNA testing?

Biology ≠ identity

DNA answers questions about our biology. But biology isn't everything!



EXAMPLE

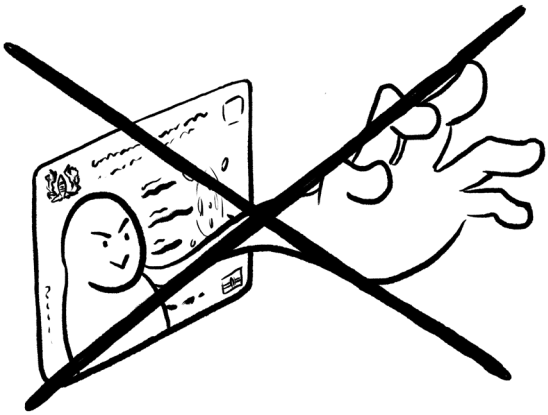
In mid-2019, it was reported that the Immigration and Customs Enforcement (ICE) in the United States was using Rapid DNA testing at the US-Mexico border, to identify individuals who were not biologically related through a parent-child relationship, whom they accused of committing "family fraud."

Or: Someone's genetic code might show them as being of the female sex, but how that sex translates to the way they choose to live their lives is a completely different issue. Gender is a construct - so sex assigned at birth can tell you very little about what gender someone is or is not.

Increase in DNA testing → **Increase in DNA databases**

As commercial companies conduct more DNA tests, they build up their own DNA databases. The same is true for law enforcement, government agencies, and other interested parties. Holding DNA databases can give institutions a lot of power - and put people represented in those databases at risk.

EXAMPLE



In 2019, the Kenyan government proposed collecting DNA as part of their new, mandatory, national ID system. It would have been the most privacy-invasive national ID system in the world. Thanks to coordinated advocacy and litigation efforts from Kenyan civil society, the proposal didn't go through.

The rise in DNA databases brings a whole new set of RISKS

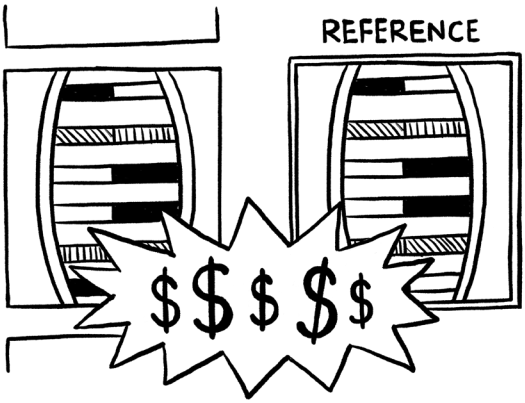
Security risks - no database is 100% secure, and a large DNA database could be an attractive target for malicious actors. Plus, DNA stays the same forever. If there's a data breach, there's no way of "updating your DNA" in the way you might update your password.

EXAMPLE

In 2019, researchers showed that website GEDMatch, where more than a million people have uploaded genetic information, was vulnerable to leaks or hacks. The site purports to only show high-level genetic information, not details, but the researchers were able to alter resolution of graphics shown on the site to uncover sensitive genetic information.

Genetic discrimination - legislation in some countries currently prohibits this, but results of people's DNA tests could be used to discriminate against them.

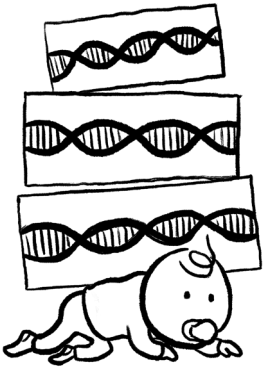
EXAMPLE



People carrying a gene that makes them more susceptible to a certain disease could be charged higher insurance premiums.

Multigenerational consequences - because DNA is connected not only to our living relatives, but also our ancestors and our descendants, whichever database you're in can also be used to identify your living relatives and even as-yet unborn future generations.

EXAMPLE



As legislation has yet to catch up to the realities of DNA databases and testing, it's impossible to say how these databases might be used in the future.

Networked consequences - what your biological relatives do with their DNA can also affect your own life, and vice-versa.

EXAMPLE

People who carry out DNA tests out of curiosity sometimes uncover hidden family secrets that can change their lives - like identifying unacknowledged brothers or sisters, or showing that a parent is not their biological parent, thanks to DNA matching with biological relatives who have used the same testing platform. The major DNA testing companies now have specially trained staff to deal with these particularly sensitive issues that arise as a result of use of their services.

Multipurpose usage - because DNA has so many uses, a database created for one purpose could be used for something very different.

EXAMPLE

23andMe will partner with a firm backed by billionaire Richard Branson - which could allow different companies and investors to have access to the vast dataset that they've gathered, depending on how well privacy statements are adhered to.

In short:

DNA can reveal just part of a picture, not the whole picture.

Risks and failures arise when DNA is used as the only answer.

The most useful and impactful uses of DNA are when it is used in combination with other pieces of information - like oral histories, family stories, public documents, or advice from genetic counselors - to better understand families or histories, and help interpret the results. In order to ensure that whatever happens with DNA doesn't have harmful long-term impacts, it also needs to be used in ways that robustly protect individual and community privacy.

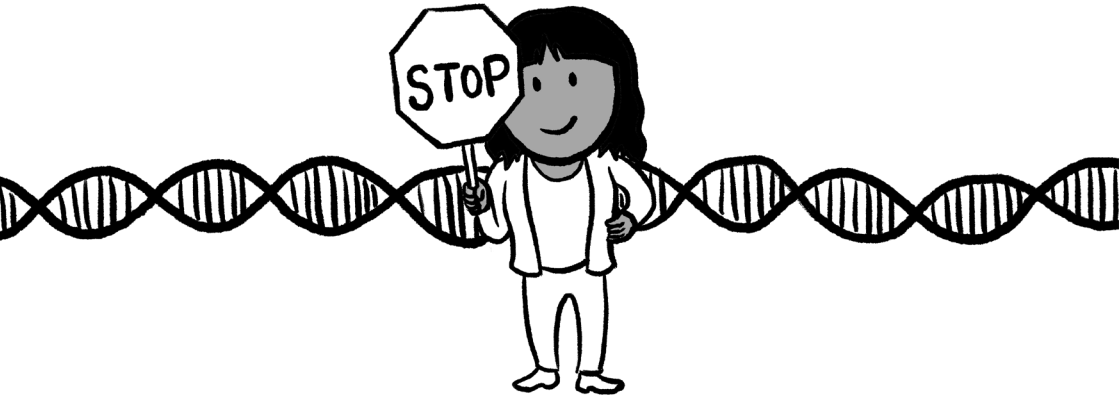
While legislation has to catch up with the new risks DNA brings - be careful what you (and your family) do with your DNA! It could have much bigger impacts than you imagine...

What you can do about it

- **Avoid giving away your DNA if you can.** Are there other (non-DNA) ways that you can find answers to the questions you want answered?

- **Make use of data protection legislation to protect yourself.** If you really want to do a DNA test, consider using data protection legislation to request that your data is deleted after you've received the results.

- **Raise awareness in your family and community.** It's easy to get caught up in the hype of DNA tests - do those close to you understand the longer-term consequences of DNA testing?



Further reading

Books

The Social Life of DNA: Race, Reparations, and Reconciliation After the Genome, by Alondra Nelson

The Postgenomic Condition: Ethics, Justice, and Knowledge After the Genome, by Jenny Reardon

Native American DNA: Tribal Belonging and the False Promise of Genetic Science by Kim TallBear

To learn more about the examples mentioned:

P6, The Grandmothers of the Plaza de Mayo:
https://abuelas.org.ar

P7, Josiah Sutton:
https://innocenceproject.org/cases/josiah-sutton

P9, Dr. Maria Nieves-Colón's work:
https://mnievescolon.weebly.com

P11, Kenya's proposed digital ID system:
https://catalystsforcollaboration.org/case-study-kenyas-biometric-id-system