The GRACE project

Direct-to-consumer (DTC) Genetic Testing

Narrator:
Have you ever seen these advertised?

These are called direct-to-consumer, or DTC, genetic tests.

This means you can buy and carry out one of these tests at home, simply by spitting in a tube!

Did you know, more than one in 20 people in the UK have already taken a DTC genetic test?

Companies selling these tests often make big promises about what their tests can do using our DNA, from predicting things about our health and ancestry, to whether someone is likely to prefer chocolate or vanilla ice cream.

But what can these tests actually tell us?

Ancestry
Benefits
DTC ancestry tests give information on where a person's ancestors came from by comparing their DNA to others from all around the world.

This can give clues about someone's ethnicity and family history, and even help find unknown relatives by matching their DNA to others who have taken the same test.

Risks
But DTC ancestry tests aren't always accurate, as ethnicities are difficult to fit into neat groups and instead form more of a gradient, like a colour palette.

Because of this, DTC ancestry reports often combine many smaller related groups together into larger more general groups, which are easier to tell apart but less precise.

Different DTC genetic testing companies also use different data and calculations to estimate someone's ancestry, and there's always some variability when dealing with so much data.

This means even genetically identical twins can get very different results from an ancestry test.

You may have also heard stories about people accidentally uncovering family secrets using at home genetic tests, like a child finding out their father isn't biologically related to them.

This can be unexpected and upsetting for the person taking the test and their family, who may wish they were told earlier or rather have not known this information at all.

Traits

Benefits

DTC trait tests are designed to predict someone's unique characteristics just by looking at their DNA.

This is fun and works well for some traits which have a simple genetic cause, like eye colour.

Risks

But some DTC testing companies claim they can predict all kinds of strange traits, such as whether someone is genetically likely to prefer chocolate or vanilla ice cream.

Most traits, like height, depend on lots of gene changes, which interact with our lifestyle choices and things in our environment.

DTC genetic tests often miss out a lot of these gene changes, and ignore environmental and lifestyle factors, so their predictions aren't always accurate.

On their own, many of the gene changes these tests do check for have a very small impact on whether someone has a certain trait.

This can be even less than a 1% chance.

So don't expect DTC genetic tests to give perfect predictions for all traits, especially the more random ones.

Health

Benefits

DTC health tests can tell us about our health by looking at our DNA for changes which raise our risk of getting certain diseases in the future or passing a health condition onto our children.

These tests mostly look for a few well-known changes linked to common diseases, like Alzheimer's disease.

Knowing this can help people to make healthy choices to reduce their risk or encourage them to have regular health check-ups.

As we share genetic information with our family members, DTC health tests can tell us whether a disorder may run in someone's family and if their relatives should also do a test to check their own risk.

Risks

But DTC genetic tests can't tell for certain if someone will develop health issues in the future. Our risk for many common diseases, like heart disease, comes from a combination of lots of different gene changes, plus our environment and lifestyle choices.

DTC genetic tests don't look at all these gene changes, but instead only check for a few which affect our risk for certain diseases while missing many others out.

And they don't account for the important effects our environment and lifestyle choices have on our health.

DTC genetic tests also aren't very accurate at calculating health risks as they don't go through the same quality checks as ones used by doctors.

This means a test might tell someone they have a low risk of a disease when their risk is high, or a high risk when it's actually low.

False results can stop people at high risk from seeking treatment they need, and make others worry or have unnecessary tests to rule something out when they're perfectly healthy.

People may also unexpectedly find out they could be at risk of a health condition because of a test taken by a close relative.

Not everyone wants to know this information, and finding out you may have a high risk for a health condition from an at home genetic test can be scary.

Compared to clinical genetic testing

If you have concerns about your health before or after taking a DTC health test, seek advice from your healthcare provider before making any big decisions.

If your doctor thinks it would be helpful for you, they can refer you for clinical genetic testing to diagnose a genetic disorder or predict your future health risks.

These tests are more accurate than DTC health tests.

They also check for many more genetic changes linked to disease risk, and include any lifestyle and environmental factors identified by your doctor, so there's less chance of false results.

You can also get support from genetic counsellors on if testing is right for you, what your results mean, and what your next steps might be.

General limitations and risks

Misleading claims

DTC genetic testing companies may make misleading claims about what their tests can do or how accurate they are, making it difficult to know how much to trust the results.

Accuracy issues by ethnicity

DTC genetic tests also tend to make their predictions using data from people of European ancestry, so the results are often even less accurate for people with other ethnic backgrounds.

Lack of support

If customers receive confusing or upsetting results, DTC genetic testing companies often don't give them enough support to answer their questions, address their worries, explain what their results mean, or give advice on next steps.

Data privacy issues

Many people also have valid questions about what DTC genetic testing companies use their genetic data for and how they keep it safe.

DTC genetic testing companies often make their own rules when it comes to data privacy, so it's important to check you feel comfortable with the company's privacy policy before taking a test.

Conclusion

We've learned that DTC genetic testing can be fun but doesn't show the full picture of our health, heritage, or unique traits, which can lead to misunderstandings and bring up worrying information.

If you're thinking about taking a DTC genetic test, first check you understand how accurate the test is, what the results might mean for yourself and your family, and how your data will be looked after.

To find out more about how to access NHS genetic testing, watch our next video.