

# My DNA will only be used in this way – busting privacy myths about DNA (INTRO)

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Webinar for the Office of the Privacy Commissioner (OPC),

New Zealand, Privacy Week 2024

17<sup>th</sup> May 2024



# What is Direct-to-Consumer Genetic Testing?

- Also known as DTC, Personal Genomics, or Commercial Genomics has created a market for DNA tests as consumer services.
- The industry operates online and internationally.
- People may send their DNA sample to a company based overseas.
- Today's talk will introduce you to this industry and some of the issues it raises, which includes problems with how we think or believe our data and DNA will be used, together with problems with privacy policies and online contracts



# Data breaches everywhere

## Hackers access profiles of nearly 7 million 23andMe customers



By [Sean Lyngaas](#), CNN

🕒 2 minute read · Updated 1:30 PM EST, Tue December 5, 2023

**Over 60 million wearable, fitness tracking records exposed via unsecured database**

**Updated: Data sources included Apple's HealthKit and Fitbit.**



Written by [Charlie Osborne](#), Contributing Writer

Sept. 13, 2021 at 9:06 a.m. PT

**UPDATED**

## Online prescription provider MediSecure suffers large-scale ransomware attack

A small e-prescription company says a major data breach was likely caused by one of its third-party vendors.

**Cyber attack on NZ's largest insurer of doctors MAS may have exposed members' personal data**

**What we know about the Medibank cyber attack and what to do if you're a customer**

# Class actions pending in the USA & Canada

## Hacking

### **Hackers got nearly 7 million people's data from 23andMe. The firm blamed users in 'very dumb' move**

The company pointed at people who 'failed to update their passwords' as sensitive data was offered for sale on forums

*Mack DeGeurin*

Thu 15 Feb 2024 14.26 GMT

 Share



<https://www.theguardian.com/technology/2024/feb/15/23andme-hack-data-genetic-data-selling-response>

# How does it work?

- Companies normally sell tests via their website
- The consumer will purchase the test online and then receive a test kit in the mail for sample collection
- The consumer takes a sample, normally saliva and sends it back to the company
- The sample is then processed and sequenced
- Companies then provide test results to the consumer
- Companies often collect other personal data through surveys and some websites offer social networking functions

# Spectrum

- There is a spectrum of services available.
- Some companies providing health tests are at the better end of the spectrum, while others marketing tests, such as infidelity tests are at the other, very dubious end of the spectrum.
- We need better oversight of this industry and I encourage you to discuss these issues with family and friends.

# Common myths about DNA in this context

- Potential for sharing of your genetic information and personal data with others, including other entities:
  - Sharing with company partners, eg. pharmaceutical & insurance industries
  - Sharing with law enforcement or immigration authorities
- Potential for data to be reused for wide variety of research purposes
- Belief or trust that data is secure
- Trust in a company's privacy practices based on a privacy policy, which you did not read
- Belief that the personal genomics industry is regulated, when in fact there are significant problems with governance of the industry

# Two questions to bear in mind

- How many contracts and privacy policies do you think you have encountered online?
- How many of these do you think you have read?



# 250,000 words of app terms and conditions

Publisert 24. mai, 2016

The average consumer could easily find themselves having to read more than 250,000 words of app terms and conditions. For most people this is an impossible task, and consumers are effectively giving mobile apps free rein to do almost whatever they want.

[Read more about the Consumer Council's Appfail campaign](#)

The Norwegian Consumer Council has downloaded the terms of service and privacy policies for apps that you would find on an "average" mobile. Together they exceed the New Testament in length - and would take more than 24 hours to read out loud.

Norwegian Consumer Council

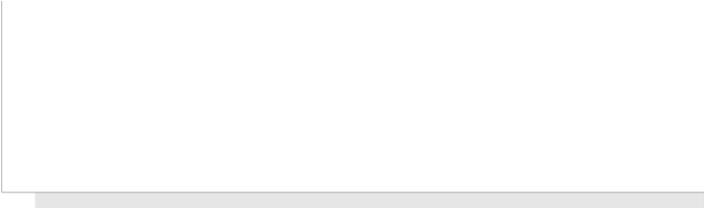
<https://www.forbrukerradet.no/side/250000-words-of-app-terms-and-conditions/>



## APPFAIL

Threats to Consumers in Mobile Apps

March, 2016



# I read all the small print on the internet and it made me want to die

Alex Hern decided not to do anything for a week - unless he'd read all the terms and conditions first. Seven days and 146,000 words later, what did he learn?



**i** Anyone else fancy reading page after page of dry, impenetrable prose? Just Alex Hern, and this guy, then ... Photograph: Sandra Baker/Alamy

<https://www.theguardian.com/technology/2015/jun/15/i-read-all-the-small-print-on-the-internet>

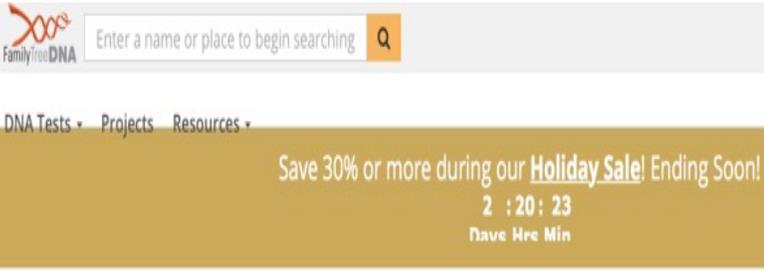
# Privacy Policies & Electronic (Wrap) Contracts

- Contracts may appear as Terms & Conditions, Terms of Service, or Terms of Use.
- Currently these documents are often linked to others, including privacy policies and contracts may incorporate terms from other documents by reference.
- In order for an individual to understand their rights, they would need to read all documents.
- This is problematic at present and reform is needed.

# Significant aspects of genetic information

- Shared with family
- Unique identifier for an individual
- Can potentially be stored indefinitely
- Does not change over time, so if something goes wrong, very hard to fix
- Possible to reidentify in quite large databases
- The risk of data leakage does not necessarily decrease over time.

# You may have heard of some prominent companies

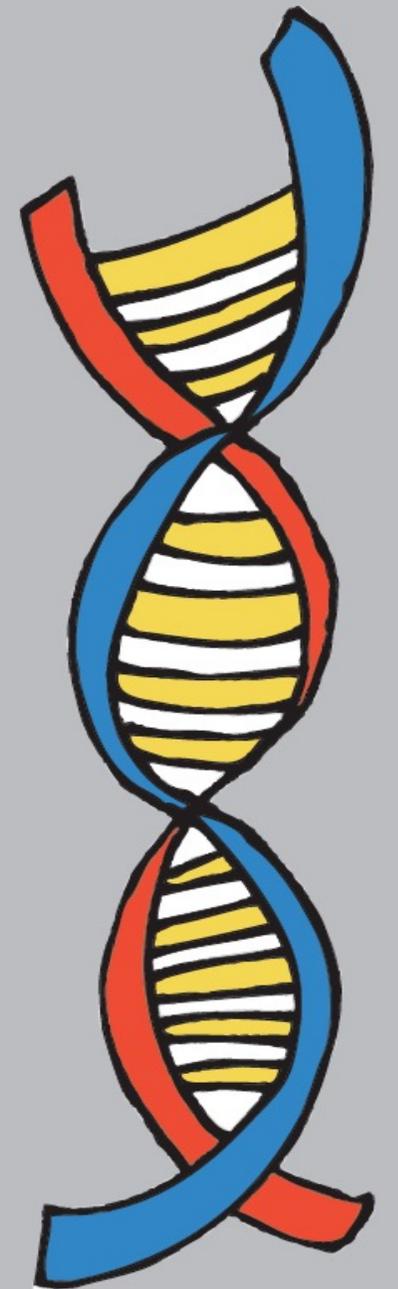


Discover the real value of AncestryDNA

With one simple test, uncover where your ancestors came from, discover distant relatives and find new details about your unique family history.

# Variety of tests available

- Health testing:
  - Carrier
  - Disease risk
  - Pharmacogenetics
  - Nutrigenetics
- Whole genome and whole exome
- Ancestry
- Child Talent
- Paternity
- Infidelity (surreptitious, non-consensual)
- Matchmaking
- Forensics



# Health Testing examples

**BASIC**



**Ancestry Service**

**MOST COMPREHENSIVE ON THE MARKET†**

If you want to start your DNA journey with ancestry and add health services later.

**\$119**

**Buy now**

**ESSENTIAL**



**Health + Ancestry Service**

Learn your risks and better understand how genetics impact your health.

**\$229**

**Buy now**

**ENHANCED**



**23andMe+ Premium™**

Stay on top of your health with an annual membership featuring ongoing personalized reports.

~~\$298~~ **\$229**

Membership renews at \$69/yr.

**Join now**

**ULTIMATE**



**23andMe+ Total Health™**

**DETECTS 200X MORE DISEASE-CAUSING VARIANTS‡**

Our most advanced health membership including next-generation sequencing.Δ

**\$999/first yr**

Membership renews at \$499/yr.

**Learn more**

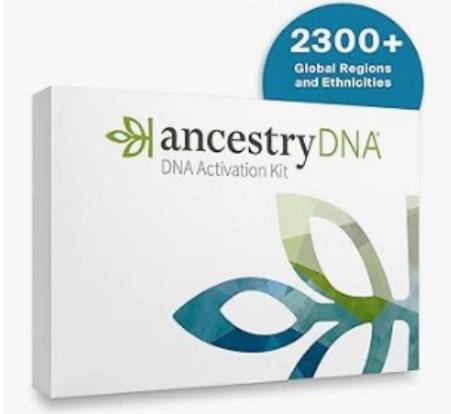
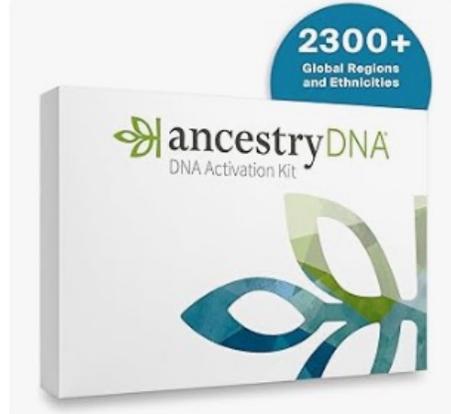
Screen shot 17 May 2024

<https://www.23andme.com/>



# Examples from Amazon AU that ship to NZ

## Results

 <p>2300+ Global Regions and Ethnicities</p> <p>ancestryDNA DNA Activation Kit</p>	 <p>+440 ITEMS</p> <p>tellmeGen™</p>	 <p>2300+ Global Regions and Ethnicities</p> <p>ancestryDNA DNA Activation Kit</p>	 <p>+440 ITEMS</p> <p>tellmeGen™</p>	 <p>+90 ITEMS</p> <p>tellmeGen™</p>
<p>Sponsored ⓘ</p> <p>AncestryDNA Genetic Test Kit: Personalized Genetic Results   DNA Ethnicity Test   Find Relatives   Origins &amp; Ethniciti...</p> <p>★★★★☆ ~ 7</p> <p>\$166<sup>23</sup></p> <p>FREE Delivery to New Zealand</p>	<p>Sponsored ⓘ</p> <p>DNA Test Advanced tellmeGen (Health + Traits + Wellness + Ancestry) What Your DNA says About You</p> <p>★★★★☆ ~ 3,246</p> <p>\$271<sup>81</sup> (\$271.81/count)</p> <p>FREE Delivery to New Zealand</p> <p>More Buying Choices \$159.00 (1 new offer)</p>	<p>AncestryDNA Genetic Test Kit: Personalized Genetic Results   DNA Ethnicity Test   Find Relatives   Origins &amp; Ethniciti...</p> <p>★★★★☆ ~ 7</p> <p>\$166<sup>23</sup></p> <p>FREE Delivery to New Zealand</p> <p>More Buying Choices \$159.00 (1 new offer)</p>	<p>DNA Test Advanced tellmeGen (Health + Traits + Wellness + Ancestry) What Your DNA says About You</p> <p>★★★★☆ ~ 3,246</p> <p>\$271<sup>81</sup> (\$271.81/count)</p> <p>FREE Delivery to New Zealand</p> <p>More Buying Choices \$260.00 (1 new offer)</p>	<p>DNA Test Starter tellmeGen. Ancestry + Traits + Wellness. What your DNA says about you</p> <p>★★★★☆ ~ 156</p> <p>\$176<sup>69</sup></p> <p>FREE Delivery to New Zealand</p> <p>More Buying Choices \$169.00 (1 new offer)</p>

Screen shot 15 May 2024

<https://www.amazon.com.au/dna-test/s?k=dna+test>



## Genetic Predisposition Test

\$675.00

HOW WOULD YOU LIKE TO RECEIVE YOUR DNA TEST RESULTS? \*

Email (standard) + \$0.00

Product total	\$675.00
Options total	\$0.00
Grand total	\$675.00

1



ADD TO CART

VIEW CART

Screen shot 15 May 2024

<https://easydna.co.nz/shop/product/genetic-predisposition-test/>

# 23ANDME DTC BREAST AND OVARIAN CANCER RISK TEST MISSES ALMOST 90 PERCENT OF BRCA MUTATION CARRIERS

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By Julia Karow

A study led by researchers at Invitae has found that 23andMe's direct-to-consumer BRCA test, which tests for three common variants in the BRCA1 and BRCA2 genes and is authorized by the US Food and Drug Administration, misses almost 90 percent of BRCA mutation carriers, both in those with and those without a personal or family history of cancer.

In addition, it misses almost 20 percent of BRCA mutations in those of self-reported Ashkenazi Jewish descent because it doesn't test for them.

The results of the study, which looked at data from almost 125,000 de-identified individuals who had been referred to Invitae for diagnostic

testing with one of the firm's cancer risk tests, was presented yesterday at the American College of Medical Genetics and Genomics annual meeting by Edward Esplin, a clinical geneticist at Invitae.

Esplin told *GenomeWeb* that the study, which did not mention 23andMe by name, was meant to criticize a screening strategy with an FDA-authorized DTC test that appears to have limited clinical utility rather than to criticize 23andMe for offering the test.

<https://www.clearityfoundation.org/23andme-dtc-breast-and-ovarian-cancer-risk-test-misses-almost-90-percent-of-brca-mutation-carriers/>

# Ancestry testing examples



# Find out what your DNA says about you and your family.

- See how your DNA breaks out across 3000+ regions worldwide with the most comprehensive ancestry breakdown on the market
- Discover relatives from near and far with our DNA Relative Finder
- Share reports with family and friends
- Learn how your DNA influences your facial features, taste, smell and other traits

Buy now

**USD\$129**

Screen shot from international version of website 17 May 2024

<https://www.23andme.com/en-int/>

## AncestryDNA®



ONLY **\$129\***

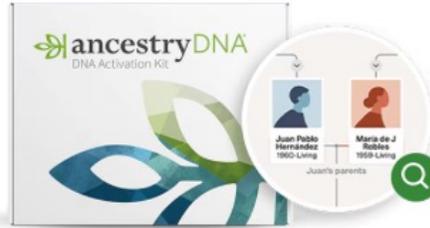
Buy now

### AncestryDNA®

Origins and Ethnicity ⓘ ✓

DNA Matches ⓘ ✓

## AncestryDNA® + 3 months World Heritage membership for you for \$1<sup>9</sup>



ONLY **\$130\***

Buy now

### What's included

### AncestryDNA®

Origins and Ethnicity ⓘ ✓

DNA Matches ⓘ ✓

### World Heritage Membership

Australia, New Zealand, and  
Int'l. Records ⓘ ✓

Traits ⓘ ✓+

DNA Inheritance ⓘ ✓+

## AncestryDNA® + Traits



ONLY **\$159\***

Buy now

### AncestryDNA®

Origins and Ethnicity ⓘ ✓

DNA Matches ⓘ ✓

Traits ⓘ ✓

Screen shot 15 May 2024

<https://www.ancestry.com.au/dna/>

Mother's Day Sale, now through May 15: Family Finder \$59 & mtDNA \$119. Save even more when you bundle!

## Find your story through her story.

Discover more about Mom's ancestry, and save big when you buy Family Finder™ + mtFull Sequence.



### Family Finder

ONLY **\$59** USD

Save \$20 (was \$79)

Add to cart

### Family Finder + mtFull Sequence

ONLY **\$169** USD

Save \$69 (was \$238)

Add to cart

### mtFull Sequence

ONLY **\$119** USD

Save \$40 (was \$159)

Add to cart



Screen shot 15 May 2024

<https://www.familytreedna.com/>

# MyHeritage DNA

Uncover your ethnic origins and find new relatives with our simple DNA test.



## MyHeritage DNA kit

Only NZ\$65 ~~NZ\$169~~ + shipping

\* Price includes applicable taxes and excludes shipping charges

Order now

- ✓ Discover your origins across 2,114 regions
- ✓ Find new relatives through shared DNA



★ BEST VALUE

## MyHeritage DNA kit + 30-day Complete free trial

Only NZ\$65\* ~~NZ\$169~~ + shipping

\* Price includes applicable taxes and excludes shipping charges

Order now

- ✓ Discover your origins across 2,114 regions
- ✓ Find new relatives through shared DNA
- ✓ Uncover your family history

Screen shot 17 May 2024

<https://www.myheritage.com/dna>



# With genetic testing, I gave my parents the gift of divorce

By George Doe | Sep 9, 2014, 7:50am EDT

f   SHARE



Tyson Whiting

[Article Link](#)

# Child talent testing examples



INBORN TALENT GENE TEST

# 46 Talents & Traits

## Maximise Your Child's Fullest Potential

The Inborn Talent Gene Test (ITGT) objective is to help parents decode their child's natural talents and aptitudes that may not be obvious at a young age. Giving your child a head start in proper nurture can maximise those aptitudes to the fullest potential.

The ITGT covers 46 talents and traits. The test reports come with a Career Profiling assessed by our team of psychologists based on one's unique abilities detected from their genetic makeup. This profile can provide an individual with good educational and career guidance. Expert Suggestions giving insightful details to help parents effectively nurture and develop their child's character and talents are also included in the report.

SHOP NOW

Screen shot 17 May 2024

<https://www.mapmygene.com/inborn-talent-gene-test/>

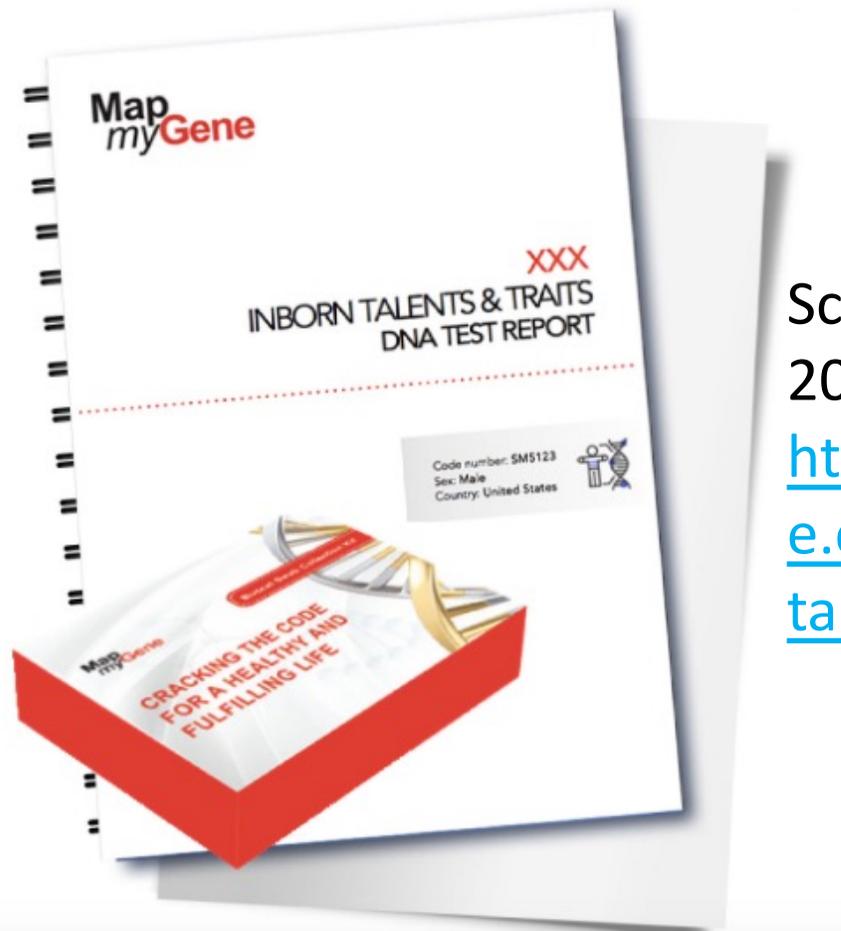
# Inborn Talent Genetic Test Kit

USD\$950.00

Map My Gene **Inborn Talent Gene Test** helps parents identify their children's natural inborn talents. It also reveals some personality traits that the child may possess, judging from his/her genetic make-up.



Add to cart



Screen shot 26 February 2024

<https://www.mapmygene.com/product/inborn-talent-gene-test-kit/>



## Time Management

Invest your efforts and time in only the right classes and developmental programs.



## Effective Planning

With the certainty of your child's innate abilities, planning for his or her future career path has never been easier.



## Big Savings

Focus more resources on the aspects that truly matter to develop your child's full potential.



## Parenting Approach

Adopt effective child discipline by adjusting your parenting strategies to suit your child's personality.



## Give your Child a Real Headstart

Give your child a headstart in life by grooming him/her according to his/her inherent talents and abilities.



## Happier Parent-Child Relationship

Avoid unwanted arguments with your child as a result of forcing him or her to do things he or she isn't good at.

Screen shot 22 March 2022

<https://www.mapmygene.com/inborn-talent-gene-test/>



## Premium DNA Test

500+ Reports • 20 Categories

Every parent hopes to nurture their child to success – but knowing how is another matter. Discover your child's hidden genetic talents and help them achieve their highest potential.



Detailed, personalised reports that help you determine: ^

- Your child's predisposition to academic achievement, entrepreneurship, mathematic talent, and more



Plus, 500+ more reports including ▾



Convenient at-home saliva collection with free pick-up



Complimentary 30-minute genetic consultation included

### Save with bundles



2x Premium DNA Test

A\$1,050 **-20% OFF**

A\$ 840 /kit



1x Premium DNA Test

A\$ 1,050

Buy now

Screen shot 27 February 2024

<https://circledna.com/en/goal/success>

# Surreptitious / Infidelity testing examples

Other Tests

# Infidelity DNA Testing

From \$683

Cheating is no longer about guess work. Our infidelity DNA test is ideal to help provide a good indication of whether or not cheating has taken place. Clients can send in a variety of different samples which have roused their suspicions. An infidelity test can be carried out using a range of DNA samples including nail clippings and hairs. Once the DNA samples are at our laboratory, you will receive your comprehensive DNA analysis report in 10 working days.

**Postal and Delivery times are constantly changing. Whilst every effort is made to reduce time where possible this cannot always be achieved due to actions outside our control. The times quoted are from the time the final sample is received.**

Please note that prepaid return postage is not included.

Order Now



Screen shot 15 May 2024

<https://easydna.co.nz/dna-tests/dna-infidelity-test/>

Dr Andelka M. Phillips, 17 May 2024



< All tests

# Infidelity DNA Test

Do you suspect infidelity? Do you want to end those gnawing suspicions and find out whether your partner is really cheating on you? International Biosciences offers infidelity DNA testing – a scientific test that can help you draw conclusions about your partner's fidelity.

**Postal and Delivery times are constantly changing. Whilst every effort is made to reduce time where possible this cannot always be achieved due to actions outside our control. The times quoted are from the time the final sample is received.**

ORDER NOW

\$683



Screen shot 15 May 2024

<https://ibdna.co.nz/tests/infidelity-dna-testing/>

# Privacy in the DTC context

- DTC companies often offer family finder features to connect individuals with others to whom they may be related.
- They often provide social networking features, where people can share information with others.
- This poses difficulties when it comes to account deletion
- Companies also often conduct research based on consumers' data

# Thinking about unique identifiers

- A good example to explain why this is important is to compare it with a ***bank password***.
- If something goes wrong you can change your password.
- You cannot change your sequenced genomic data.

# Is data totally secure? – Probably not

Jonathan Greig

February 24, 2023

Briefs

Cybercrime

Government

Malware



## DNA Diagnostics Center to pay \$400,000 fine for 2021 data breach

One of the largest commercial DNA testing companies in the world agreed to pay a \$400,000 fine to Ohio and Pennsylvania after a 2021 data breach **compromised the information of more than 2 million people.**

The announcement from DNA Diagnostics Center (DDC) comes after a lawsuit filed by the two states' attorneys general accused the company of waiting three months to even acknowledge the breach.

"The more personal information these criminals gain access to, the more vulnerable the person whose information was stolen becomes," Pennsylvania's Acting Attorney General Michelle Henry **said.** "That's why my Office took action with the assistance of Attorney General Yost in Ohio."

Of the 2.1 million people who had data leaked, 12,663 were from Pennsylvania and 33,282 were from Ohio. The leaked information included Social Security numbers and healthcare data.

Prosecutors for both states said the issue began with DDC's **2012 acquisition of Orchid Cellmark's government paternity business.**

<https://therecord.media/dna-diagnostics-center-to-pay-400000-fine-for-2021-data-breach/>

# MyHeritage data breach exposes info of more than 92 million users

*Written by a NortonLifeLock employee*

If you use MyHeritage for testing your DNA and tracking your ancestry, you may need to change your password. That's the company's guidance following a data breach that exposed email addresses and encrypted passwords for more than 92 million users.

## What happened in the MyHeritage breach

**MyHeritage said** a security researcher notified the company on June 4, 2018, of a file found on a private server outside of the company. After analyzing the file, a MyHeritage security team determined that its contents originated from the company and included the email addresses and hashed passwords of 92,283,889 users.

MyHeritage said the information exposed involved users who had signed up for the service through October 26, 2017, the date of the breach.

<https://us.norton.com/blog/emerging-threats/myheritage-data-breach-exposes-info-of-more-than-92-million-user#>

# Data breaches already occurring

- 23andMe – 2023
  - 6.9 million consumers impacted
  - Approximately half of their customers
- DNA Diagnostics Center – 2023
  - 2.1 customers consumers impacted
- MyHeritage – 2017
  - Discovered in 2018
  - More than 93 million people impacted

# Secondary Use

- Law enforcement using this as evidence in court
- Use by law enforcement to identify suspects & deceased remains
- Medical research
- Insurance industry
- Pharmaceutical industry
- Other entities, such as immigration authorities

# Golden State Killer suspect was tracked down through genealogy website GEDmatch

*A relative's genetic profile led police to the suspect*

By [Rachel Becker](#) | Apr 26, 2018, 10:51pm EDT

*If you buy something from a Verge link, Vox Media may earn a commission. See our [ethics statement](#).*

<https://www.theverge.com/2018/4/26/17288532/golden-state-killer-east-area-rapist-genealogy-websites-dna-genetic-investigation>

MEGAN MOLTENI

SCIENCE JUN 1, 2018 7:00 AM

## The Key to Cracking Cold Cases Might Be Genealogy Sites

A forensic DNA firm that works with law enforcement says it has uploaded 100 files to GEDmatch, the site that helped identify the alleged Golden State Killer.

<https://www.wired.com/story/police-will-crack-a-lot-more-cold-cases-with-dna/>



# Framed for Murder by His Own DNA

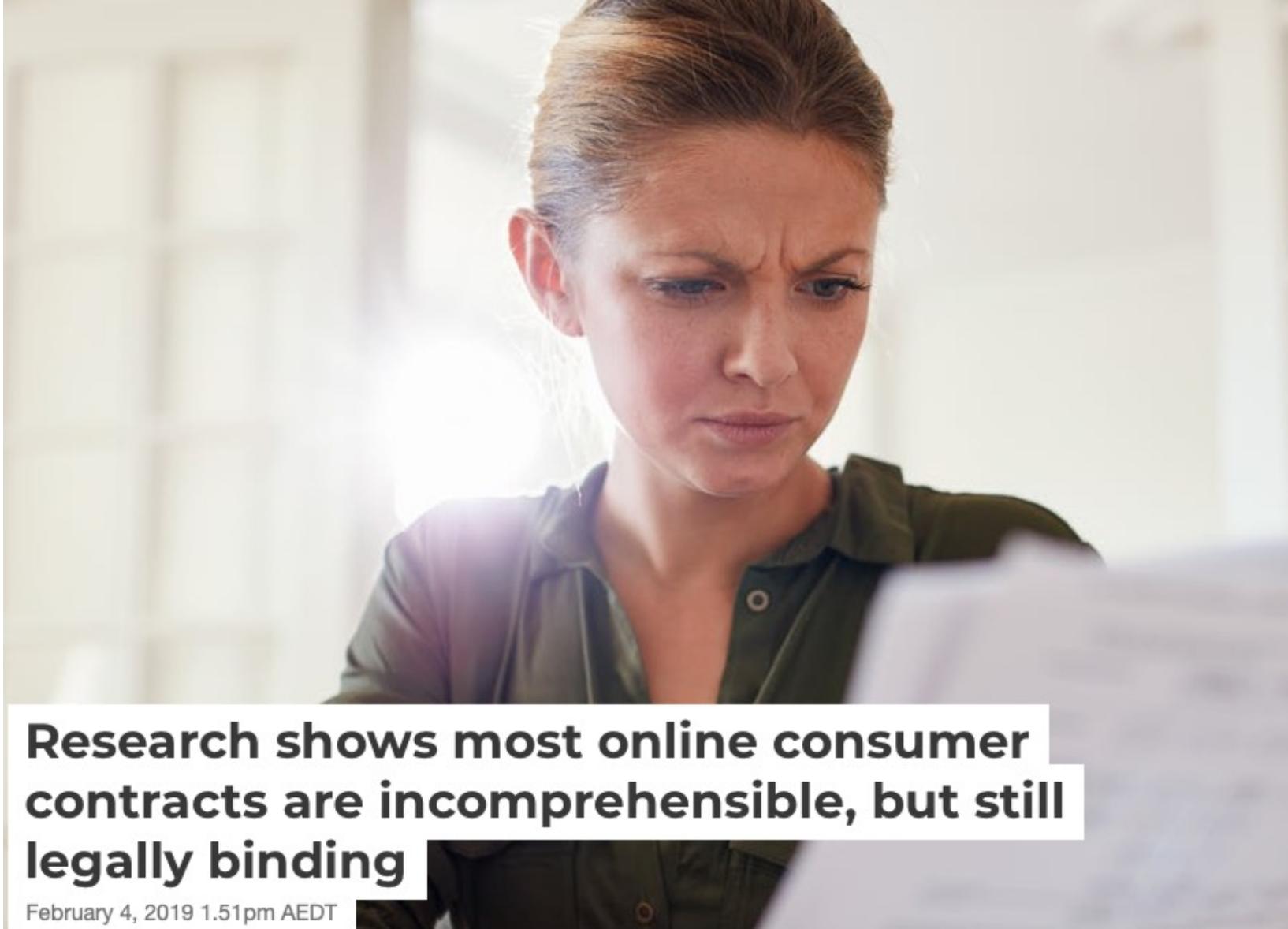
We leave traces of our genetic material everywhere, even on things we've never touched. That got Lukis Anderson charged with a brutal crime he didn't commit.



<https://www.wired.com/story/dna-transfer-framed-murder/>

# Problems of relying on contracts and privacy policies

- Who is reading?
- And who understands what they are reading?
- Often contracts include terms which could be challenged on the basis of unfairness
- Often contracts link to privacy policies and allow for significant changes to how data is used



## Research shows most online consumer contracts are incomprehensible, but still legally binding

February 4, 2019 1.51pm AEDT

<https://theconversation.com/research-shows-most-online-consumer-contracts-are-incomprehensible-but-still-legally-binding-110793>

GAMES

# GameStation EULA collects 7,500 souls from unsuspecting customers

BY JOHN BROWNLEE 04.16.2010 :: 4:50PM EST

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<https://www.geek.com/games/gamestation-eula-collects-7500-souls-from-unsuspecting-customers-1194091/>

The exact wording of the soul clause in GameStation's terms and conditions read:

**By placing an order via this Web site on the first day of the fourth month of the year 2010 Anno Domini, you agree to grant Us a non transferable option to claim, for now and for ever more, your immortal soul. Should We wish to exercise this option, you agree to surrender your immortal soul, and any claim you may have on it, within 5 (five) working days of receiving written notification from gamesation.co.uk or one of its duly authorised minions. We reserve the right to serve such notice in 6 (six) foot high letters of fire, however we can accept no liability for any loss or damage caused by such an act. If you a) do not believe you have an immortal soul, b) have already given it to another party, or c) do not wish to grant Us such a license, please click the link below to nullify this sub-clause and proceed with your transaction.** 

It wasn't just a gag though: the roughly 12% of customers who clicked the links were given a free £5 voucher.

# 22,000 people willingly agree to community service in return for free WiFi

- ‘Over 22,000 people have openly agreed to carry out 1,000 hours of community service after we added the spoof clause into our terms and conditions over a two-week period.’
- ‘A “Community Service Clause” was added to our usual terms and stated: The user may be required, at Purple’s discretion, to carry out 1,000 hours of community service. This may include the following:
  - Cleansing local parks of animal waste
  - Providing hugs to stray cats and dogs
  - Manually relieving sewer blockages
  - Cleaning portable lavatories at local festivals and events
  - Painting snail shells to brighten up their existence
  - Scraping chewing gum off the streets’

# Terms Likely To Be Deemed Unfair Or Problematic

- Clauses allowing for unilateral alteration of terms
- Clauses disclaiming liability for fitness for purpose or for personal injury caused by the company's negligence
- Clauses limiting scope of purpose
- Clauses purporting to bind the consumer to resolve any disputes in another jurisdiction
- Indemnity clauses
- Certain intellectual property licences
- And consent clauses

# The Norwegian Consumer Council reports MyHeritage for unlawful terms and conditions

11. mars, 2020

The Norwegian Consumer Council is of the opinion that MyHeritage is taking unlawfully excessive liberties with people's sensitive data. It is therefore reporting MyHeritage to the Norwegian Consumer Authority and the Norwegian Data Protection Authority.

Presse: Forbrukerrådet rapporterer inn Myheritage for ulovlige vilkår



More than 25 million people have taken genetic tests worldwide, and MyHeritage is among the largest actors.

<https://www.forbrukerradet.no/side/the-norwegian-consumer-council-reports-myheritage-for-unlawful-terms-and-conditions/>



# Things to consider before buying a DNA test



- And [YouTube Link](#) to animated video
- This is linked to the project ['Fairness and Transparency in Emerging Health Markets: Protecting New Zealanders from the Risks of Personal Genomics'](#)
- We are extremely grateful to the Borrin Foundation for funding this project.

# Things to consider before buying a test

1. Given the sensitivity of the information and the risks involved, are you comfortable accepting the terms and conditions you (probably) haven't read?
2. Many third parties may be interested in your genetic information. Are you happy for it to be shared with them?
3. Do you realise you don't have the legal right to decide how long your personal data will be stored?
4. If you're considering a test because of a health concern, did your doctor recommend it?
5. How would you respond if your ancestry results don't match your sense of identity?
6. How would you feel if the company changed its policy and restricted your access to your own data?

From our piece in the Conversation

<https://theconversation.com/at-home-dna-tests-just-arent-that-reliable-and-the-risks-may-outweigh-the-benefits-194349>

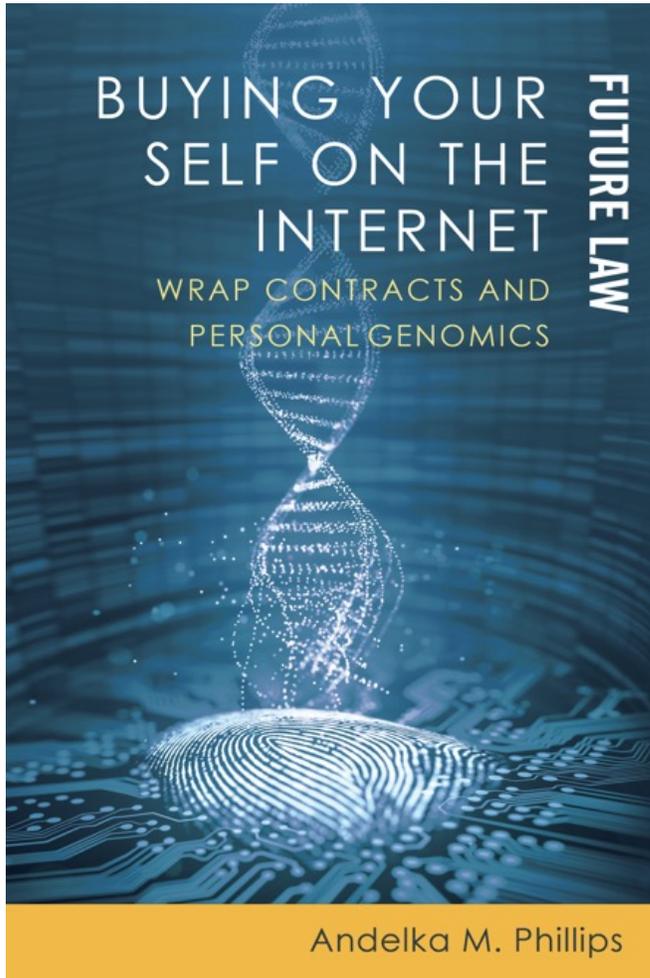
# Suggestions for reform

- Need to improve and harmonise standards
- Better enforcement & compliance with existing law (privacy/data protection, consumer protection, and other applicable law).
- Need for collaboration between regulators internationally.
- Need to develop further governance mechanisms if police are going to use these companies in investigations. Take account of NZ Law Commission recommendations.
- Need for improved transparency
- Regulatory reform – industry specific new legislation
- Compliance reviews/audits

# Further suggestions

- Need to improve cyber security across the industry
- More oversight of what businesses actually do with consumers' data – what happens when companies merge
- Employing the consumer data right in this context
- Better contracts and privacy policies that consumers can understand
- Model contracts & privacy policies
- Need for consultations and frameworks to be developed in relation to using this data in the courts
- Mandatory codes of conduct and codes of practice that are adhered to by industry
- Possible role for competition law here as well

# Related publications



- AM Phillips, *Buying Your Self on the Internet: Wrap Contracts and Personal Genomics* (Edinburgh University Press 2019) [JSTOR Link](#) & publisher [Link](#)
- AM Phillips, 'Hacking your DNA? Some things to consider before buying a DNA test online' Health Law Blog Sweden (2 March 2024) [Link](#)
- AM Phillips, 'Owning me, owning you – How private companies acquire rights in our most intimate data' in forthcoming volume G Reynolds, A Mogyoros, and T Dagne (eds), *IP's Futures* (University of Ottawa Press 2024)
- SI Becher and AM Phillips, 'Data Rights and Consumer Contracts: The Case of Personal Genomic Services' in D Clifford, KH Lau, and J Paterson (eds), *Data Rights and Private Law* (Hart Publishing, 2023). [Link](#)
- AM Phillips and SI Becher, 'At-home DNA tests just aren't that reliable – and the risks may outweigh the benefits' *The Conversation* (29 November 2022) [Link](#)
- AM Phillips, 'Reading the Fine Print When Buying Your Genetic Self Online: Direct-to-Consumer Genetic Testing Terms and Conditions' (2017) *New Genetics and Society* 36(3) 273-295. [Link](#)

# Thank you

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- <https://www.bioethics.ugent.be/our-people/andelkamphillips/>



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