

Sharing Our Most Sensitive Data in an Age of Future Risk

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Privacy Week 2026, 11th May 2026



Privacy Week 2026
11 - 15 May
privacy.org.nz



Introduction

- We are living in a data driven age where rapid deployment of Artificial Intelligence in a wide variety of contexts is contributing to increasing privacy risks on a massive scale.
- This webinar will provide an overview of risks for privacy in the context of services that rely on sensitive data.
- This will consider the example of the personal genomics industry and the 23andMe data breach and its aftermath.
- It will also consider some related examples of other industries that rely on sensitive data, such as online data.
- It will include suggestions for key questions to consider when we share our sensitive data and make suggestions for reform.

The Age of GenAI, Data Breaches, & Future Risk

- “It only took nine seconds for an AI coding agent gone rogue to delete a company’s entire production database and its backups, according to its founder. PocketOS, which sells software that car rental businesses rely on, descended into chaos after its databases were wiped, the company’s founder Jeremy Crane said.”
- “The culprit was Cursor, an AI agent powered by Anthropic’s Claude Opus 4.6 model, which is one of the AI industry’s flagship models. As more industries embrace AI in an attempt to automate tasks and even replace workers, the chaos at PocketOS is a reminder of what could go wrong.”
 - <https://www.theguardian.com/technology/2026/apr/29/claude-ai-deletes-firm-database>

Direct-to-Consumer Genetic Testing (DTC)

- 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.
- A customer orders a test on the website and is sent a kit in the mail to collect their saliva or do a cheek swab
- People may send their DNA sample to a company based overseas – often Kiwis will be sending samples to an American company
- You may be aware of the 23andMe data breach and its aftermath

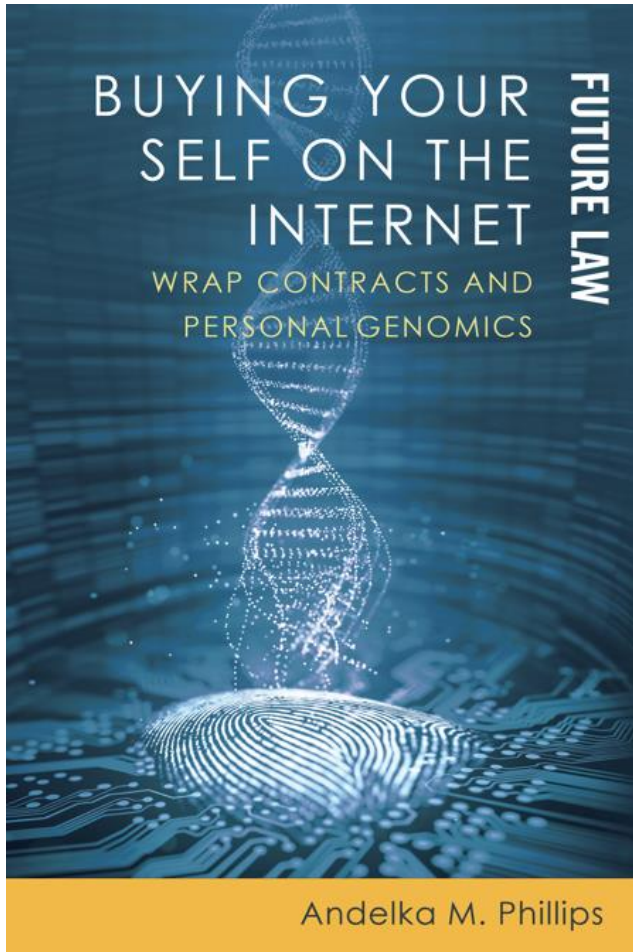
Direct-to-consumer genetic testing

- This industry has created a market for DNA tests as consumer services
- This takes these tests outside existing governance and legal requirements that apply in a medical context
- The industry operates internationally raising challenges for Privacy and Data Protection Law as well as Consumer Protection

My previous has considered DTC, as well as:

- Wearable technology – watches, bands & rings
- And online dating
- My future work will consider several other industries that rely on sensitive data, eg. online dating, Mental Health Apps, and the use of of Chatbots for Mental Health advice

My work on direct-to-consumer genetic testing



- The book is now available in full through Perlego and OUP & direct from [Edinburgh University Press](#)
- Andelka M. Phillips, '[Owning me, owning you – How private companies acquire rights in our most intimate data](#)' in Graham J. Reynolds, Alexandra Mogyoros, and Teshager Dagne (eds), *Intellectual Property Futures – Exploring the Global Landscape of IP Law and Policy* (University of Ottawa Press 2025) - [Open Access Link](#).
- Andelka M. Phillips, '[Their Best Intentions Don't Mean Much – Sale of Your Genetic Data was Always on the Cards](#)' Health Law Blog (18 June 2025)
- Andelka M Phillips and Samuel Becher, '[At-home DNA tests just aren't that reliable – and the risks may outweigh the benefits](#)' The Conversation (29 November 2022)
- Andelka M 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 <http://dx.doi.org/10.1080/14636778.2017.1352468>

Recent news

Number of AI chatbots ignoring human instructions increasing, study says

Exclusive: Research finds sharp rise in models evading safeguards and destroying emails without permission

MediMap hack investigation after patients wrongly marked dead, names changed

UK Biobank breach is part of a growing threat to medical research

'The math is simple': OpenClaw 'Trojan Horse' AI agents give hackers full control of 28,000+ systems

News By Efosa Udimwun published 22 April 2026

Hackers are exploiting poorly secured AI agents at scale

UK Biobank health data listed for sale in China, government confirms

New Zealand students' details caught up in massive global university hack

LILY HAY NEWMAN

ANDY GREENBERG

SECURITY

MAY 8, 2026 1:02 AM

The Canvas Hack Is a New Kind of Ransomware Debacle

Thousands of schools around the US were paralyzed on Thursday after education tech firm Instructure shut down access to its Canvas platform following a breach by hackers going by the name ShinyHunters.



AI + ML

Brit mathematician lets AI agent loose with credit card – cue password leaks, CAPTCHA chaos and more

Professor Fry's AI experiment shows light and dark sides of agentic tech

 Richard Speed

151 

Published Tue 05 May 2026 // 12:04 UTC



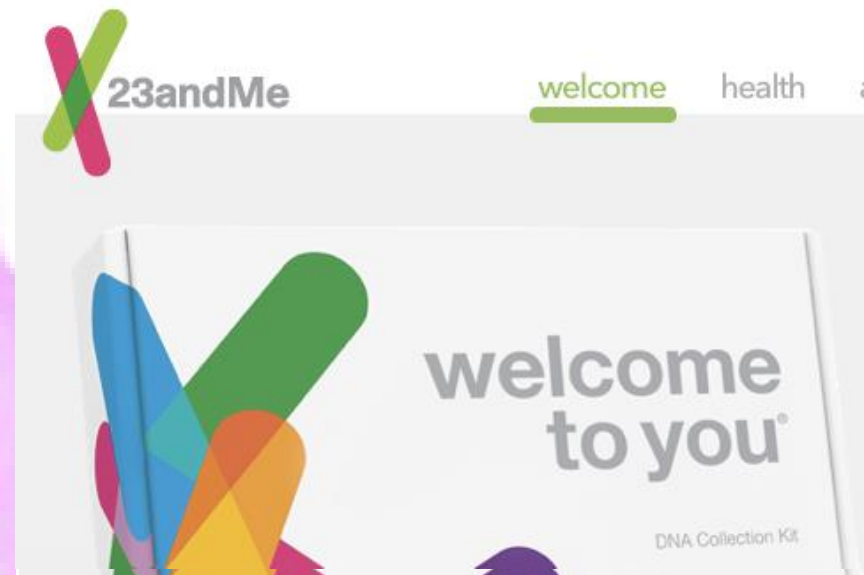
British mathematician Professor Hannah Fry has shared a cautionary experiment involving an AI agent, a set of tasks, and a bank card number Fry's team gave it "to show us what it could do."

The prof gave the agent, which was built with OpenClaw, some real-world chores to highlight both its capabilities and the risks of granting that level of autonomy.

"In the spirit of experimentation," said Fry, "we decided to give our agent some agency and let it decide what its name should be."

<https://www.theregister.com/software/2026/05/05/british-mathematician-hands-openclaw-agent-a-credit-card/5228654>

You may have heard of some prominent companies



Variety of tests available

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

Significant aspects of genetic information

- Shared with family
- Unique identifier for an individual
- Can potentially be stored indefinitely
- Possible to reidentify in quite large databases
- The risk of data leakage does not necessarily decrease over time.

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.

Some examples of DTC DNA testing website content



A gift that keeps giving.

A Mother's Day gift that gives her meaningful health insights she can use for years to come.

Get started

20% OFF

Basic Ancestry

Explore the unique story written in your DNA, from your global ancestry breakdown out of 4,500+ regions to the relatives who share your genetic legacy.



~~\$99~~

\$79

20% OFF

Learn more

55% OFF

Advanced Ancestry + Health

Membership fueled by discovery, sharpened by time. Provides 100+ genetic insights and action tools.



~~\$199~~

\$80*

55% OFF

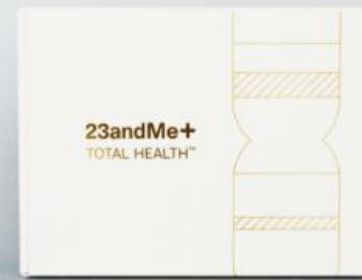
FSA & HSA Eligible

Learn more

20% OFF

Ultimate Health + Advanced Ancestry

Our most advanced health kit. Includes next-generation DNA analyses and blood testing to provide cutting-edge longevity insights and guidance toward a healthier you.



~~\$499~~

\$399*

20% OFF

FSA & HSA Eligible

Learn more

Screen shot, 10 May 2026, <https://www.23andme.com/>

Dr Andelka M. Phillips, 10 May 2026

The image shows the packaging for the AncestryDNA DNA Activation Kit. The box is white with a green and blue leaf-like graphic on the right side. The text on the box reads "ancestryDNA" in a green and black font, with "DNA Activation Kit" in a smaller black font below it.

ancestryDNA[®]
DNA Activation Kit

Discover the people and places in your past, with AncestryDNA

- Origins from 3,600+ places
- Historical & geographical insights
- DNA Matches
- DNA by Parent

ONLY **\$129***

Buy now

*AUD. Excludes shipping, includes taxes. Transaction fees may apply. Payment processed in the United States.

Screen shot, 10 May 2026, <https://www.ancestry.com.au/c/origins>

Prenatal Package available from \$2,099

Home Paternity Test available from \$345

✓ Fast











✓ Affordable

✓ Reliable

✓ ISO 17025

Order Now



 Paternity Tests	 Relationship Tests	 Prenatal Tests	 Ancestry Tests
 Health & Wellbeing Tests	 Oncology Tests	 Clinical & Molecular Tests	 Animal Tests
 Other Tests	 Drug Tests		

Screen shot 10 May 2026, <https://easydna.co.nz/>

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 21 March 2025

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

Dr Andelka M. Phillips, 10 May 2026

Inborn Talent Genetic Test Kit

USD\$1200.00

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.

1

Add to cart



Screen shot 18 February 2026

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



Time Management

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



Effective Planning

With the certainty of your child's innate abilities, planning for their 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 them according to their inherent talents and abilities.

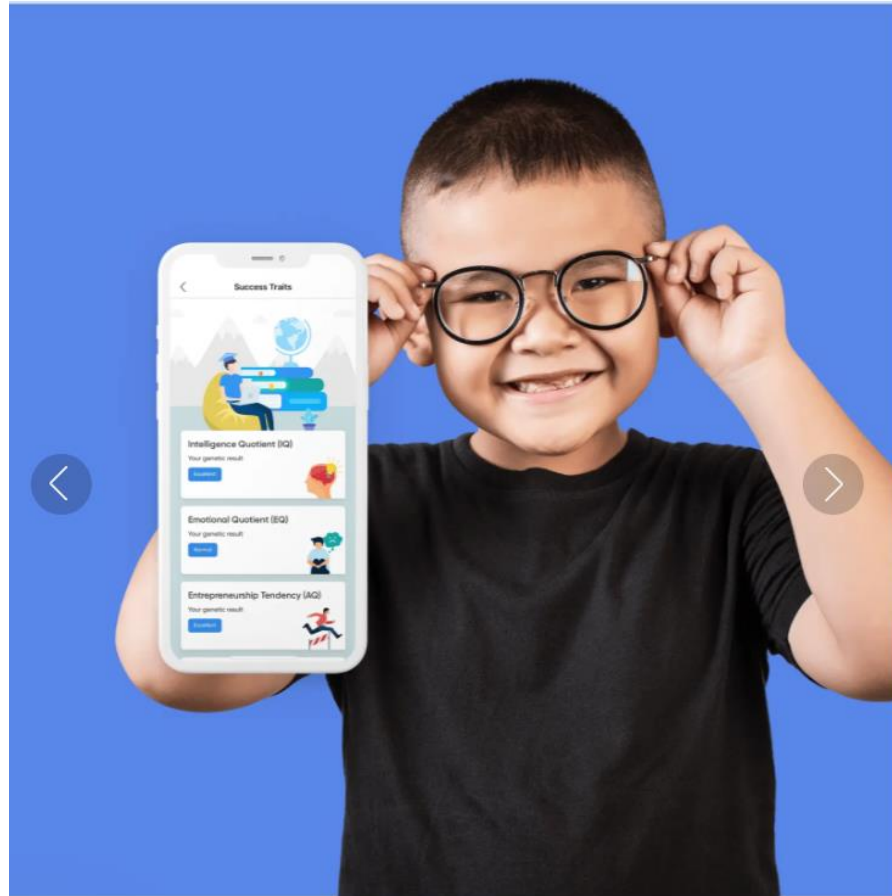


Happier Parent-Child Relationship

Avoid unwanted arguments with your child due to forcing them to do things they aren't good at.

Screen shot 21 March 2025





<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 Save A\$471

A\$ 579 /kit



1x Premium DNA Test

A\$1,050 Save A\$471

A\$ 579

Buy now

Screen shot 21 March 2025

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

Contracts, Privacy Policies, Consent & Data Breaches

23andMe class action settlement



If you were a U.S. customer of 23andMe at any time between May 1, 2023 and October 1, 2023 and received notice that your personal information was compromised in a Cyber Security Incident

You are eligible for benefits from this Settlement.

The U.S. Bankruptcy Court has authorized this Settlement Website. This is not a lawyer solicitation.

Final Approval of the Settlement was granted by the Court on January 30, 2026. The Order is available on the [Documents](#) page of this website. The Claims period is still open. Settlement payments will not be distributed until the Bankruptcy reconciliation process is resolved, which may take several months or longer. Please check this website for updates.

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



SECURITY



23andMe tells victims it's their fault that their data was breached

Lorenzo Franceschi-Bicchierai — 8:42 AM PST · January 3, 2024

<https://techcrunch.com/2024/01/03/23andme-tells-victims-its-their-fault-that-their-data-was-breached/>

Court approves sale of 23andMe to nonprofit led by former CEO Anne Wojcicki

The company's assets include genetic data belonging to 15 million customers.

By [Max Zahn](#)

July 1, 2025, 2:53 PM



<https://abcnews.com/Business/court-approves-sale-23andme-nonprofit-led-former-ceo/story?id=123369272>

23andMe fined £2.31 million for failing to protect UK users' genetic data

- ICO has fined 23andMe
- "Between April and September 2023, a hacker carried out a credential stuffing attack on 23andMe's platform, exploiting reused login credentials that were stolen from previous unrelated data breaches."
- "This resulted in the unauthorised access to personal information belonging to 155,592 UK residents, potentially revealing names, birth years, self-reported city or postcode-level location, profile images, race, ethnicity, family trees and health reports. The type and amount of personal information accessed varied depending on the information included in a customer's account."
- "Our investigation found that 23andMe did not have additional verification steps for users to access and download their raw genetic data."
 - <https://ico.org.uk/about-the-ico/media-centre/news-and-blogs/2025/06/23andme-fined-for-failing-to-protect-uk-users-genetic-data/>

23andMe class action settlement – very little compensation for harm

- 'You are a Settlement Class Member if you (a) were a 23andMe customer at any time between May 1, 2023 through October 1, 2023; (b) resided in the U.S. during this time; and (c) received notice from 23andMe that your personal information was compromised.
- You may be eligible for a cash payment and other benefits from a class action settlement:
 - Up to \$10,000 for Extraordinary Claims;
 - Up to \$165 for Health Information Claims;
 - An estimated \$100 for Statutory Cash Claims; and
 - 5 years of Privacy & Medical Shield + Genetic Monitoring'
 - <https://www.23andmedatasettlement.com/>



Do you think this is a fair result?

- While the total figure of \$30 million USD may seem high, I urge you to consider the reality of harm that a person could suffer from this breach.
- Consider health insurance in the USA
- Consider the possibility of identity theft
- Consider the possibility that individuals and families to be targeted due to their race
- What about other offences?

There could not be anything bad buried in your those Terms & Conditions or that Privacy Policy right?



Nobody Reads Terms & Conditions: GameStation's Immortal Soul clause


- "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"

- See <https://www.pinsentmasons.com/out-law/news/nobody-reads-terms-and-conditions-its-official>

- And you can see more of this on the next slide Wayback Machine 'GameStation EULA collects 7,500 souls from unsuspecting customers' article

<https://web.archive.org/web/20190304083732/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:

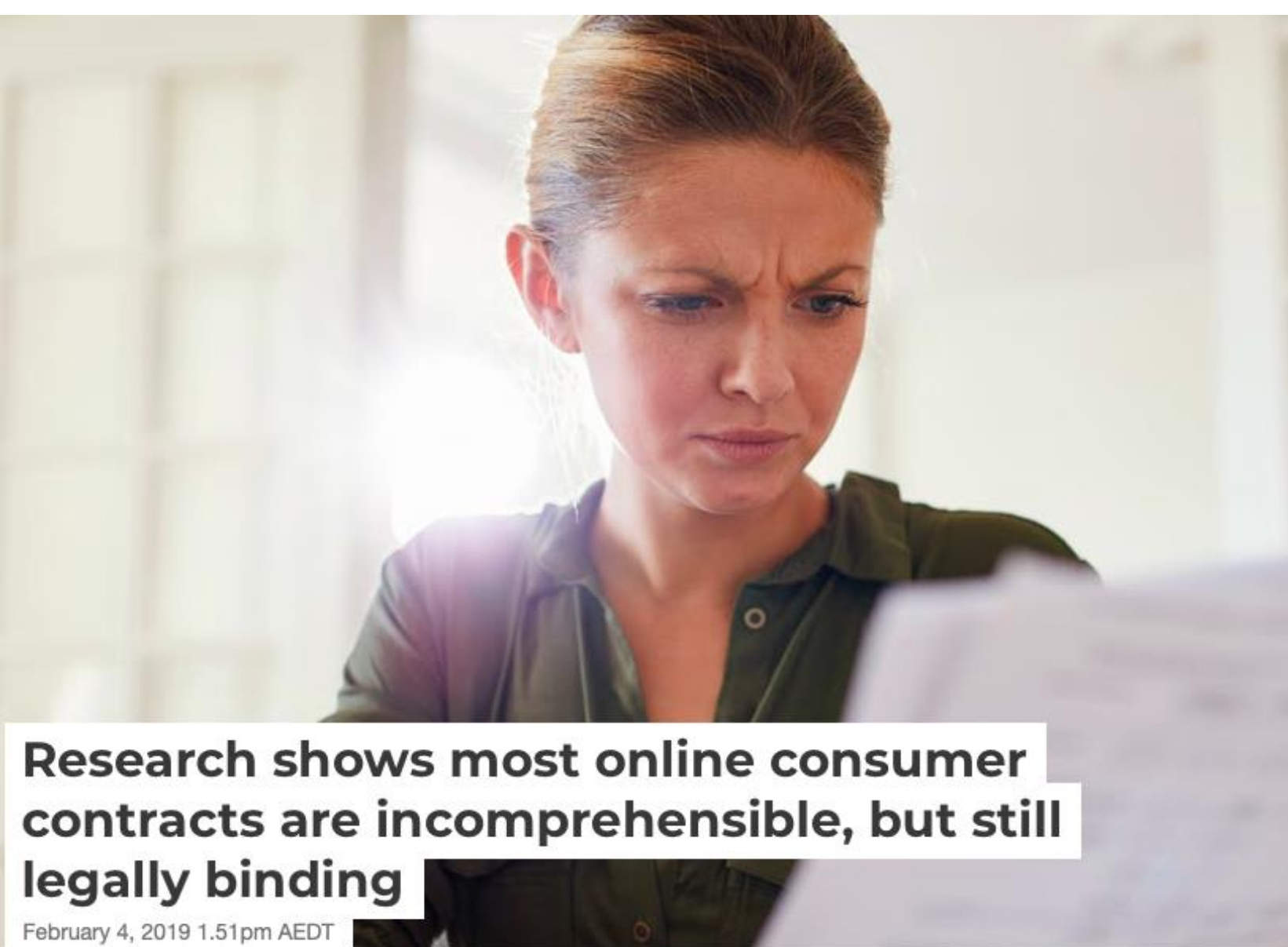
By placing an order via this Web site on the first day of the fourth month of the year 2010 Anno Domini, you agree to grant Us a non transferable option to claim, for now and for ever more, your immortal soul. Should We wish to exercise this option, you agree to surrender your immortal soul, and any 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

- ‘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’

<https://purple.ai/blogs/purple-community-service/>



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>

Problems of living in a world of contracts

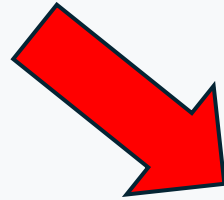
- How many contracts do you think you have entered into online?
- How many can you remember reading?
- At a broader level, do you think consumers are reading these documents?
- What do you think about the readability of these documents?
- Often contracts include terms which could be challenged on the basis of unfairness
- Transparency requirements?

Previous review of contracts of personal genomics companies - Terms Likely To Be Deemed Unfair

- 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;
- And consent clauses



How many documents?



Services	Company	Learn	Legal	Partner With Us
Health + Ancestry	Investors	About Us	Important Test Info	Healthcare Professionals
Ancestry Service	Media Center	How it Works	Terms of Service	Scientists
23andMe+ Premium	Blog	Science	Privacy Statement	Business Development
23andMe+ Total Health	Careers	Privacy	Data Protection	
Gifts	Refer a Friend	Research	Family Considerations	
Merchandise	Return & Refund Policy	Stories	Research Consent	
	Customer Care	Surname Discovery	Individual Data Consent	Download App
	FSA/HSA Eligibility	Diversity, Equity & Inclusion	Biobanking Consent	
	Site Map	Genetics Learning Hub	Cookie Policy	
		DNA & Personalized Healthcare	Cookie Choices	
			Patent Information	
			Report a Security Issue	
			Consumer Health Data Privacy Policy	

Screen shot 20 March 2025 <https://www.23andme.com>

23andMe Terms of Service – indemnity clause

- 'You agree to defend and hold 23andMe, and its subsidiaries, affiliates, officers, agents, contractors, partners, employees, successors, and assigns harmless from any claim, or demand, including reasonable attorneys' fees, made by any third party due to or arising out of User Content you submit, post to, or transmit through the Service; your use of the Service; your connection to the Service; your violation of the Terms; or your violation of any rights of another.
- If you have submitted a sample or otherwise provided your own information, you will defend and hold harmless 23andMe, its employees, contractors, successors, and assignees from any liability arising out of the use or disclosure of any information obtained from analyzing your sample and/or analyzing your information, which is disclosed to you consistent with our Privacy Statement or results from any third-party add-ons to tools we provide. In addition, if you choose to provide your information to third parties - whether individuals to whom you facilitate access, intentionally or inadvertently, or to third parties for diagnostic or other purposes - you agree to defend and hold harmless 23andMe, its employees, contractors, successors, and assignees from any and all liability arising from such disclosure or use of your information.'
- NZ site, Full Terms last updated 14 November 2025 – the same term is included on the US and UK domains
- <https://www.23andme.com/legal/terms-of-service/full-version/>

AncestryDNA – indemnity clause

- ‘You agree that you will indemnify and hold Ancestry, and its affiliates and subsidiaries their respective officers, directors, employees, agents, successors, and assigns (the “Ancestry Parties”) harmless from any claims, damages, or other expenses (including attorney’s fees) that result from your use of the Services and (a) your violation of these Terms or other documents or policies incorporated herein by reference; (b) your violation of another person’s rights; or (c) any claim related to Your Content, including a claim that Your Content caused damage to another person. This indemnification obligation will continue after you stop using the Services. In addition, you release the Ancestry Parties from all claims, demands, actions, or suits in connection with Your Content, including any liability related to our use or non-use of Your Content, claims for defamation, invasion of privacy, right of publicity, emotional distress, or economic loss.’
- Terms and Conditions for Australia and NZ (last updated 18 August 2025)
- <https://www.ancestry.com.au/c/legal/termsandconditions>

EasyDNA - indemnity

- ‘5.5 The Client agrees to indemnify the Company against all claims, expenses and any loss or damage suffered by the Company as a result of the Client (or their Sampler) passing to the Company any samples which were not legally obtained.
- 5.6 The Company strongly advises that the Client obtains independent legal advice about their entitlement to take or obtain samples of biological material from persons other than themselves....
- 5.9 The Client warrants that they are entitled to provide the Company with all information and data and shall indemnify the Company against any claims for infringement of the information or data, breaches of confidentiality or failure to comply with any data protection laws brought by any third parties.’
- Also note the company does have an NZ office, but has provided that the contract should be subject to the law of t New Mexico. – See clause 10 of the document.
- EasyDNA, Terms and Conditions
- <https://easydna.co.nz/terms-of-service/>

23andMe – Disclaimer of Warranties

- ‘YOU EXPRESSLY ACKNOWLEDGE AND AGREE THAT: (1) YOUR USE OF THE SERVICES ARE AT YOUR SOLE RISK. THE SERVICES ARE PROVIDED ON AN “AS IS” AND “AS AVAILABLE” BASIS. TO THE MAXIMUM EXTENT PERMITTED BY APPLICABLE LAW, 23ANDME EXPRESSLY DISCLAIMS ALL WARRANTIES OF ANY KIND, WHETHER EXPRESS OR IMPLIED, INCLUDING, BUT NOT LIMITED TO, THE IMPLIED WARRANTIES OF MERCHANTABILITY, FITNESS FOR A PARTICULAR PURPOSE, AND NON-INFRINGEMENT. (2) 23ANDME MAKES NO WARRANTY THAT (a) THE SERVICES WILL MEET YOUR REQUIREMENTS; (b) THE PRICES, DESCRIPTIONS OF ANY PRODUCT OR SERVICE, OR SERVICES WILL BE ERROR-FREE, UNINTERRUPTED, TIMELY, OR UNFAILINGLY SECURE; (c) THE RESULTS THAT MAY BE OBTAINED FROM THE USE OF THE SERVICES WILL BE ACCURATE OR RELIABLE; (d) THE QUALITY OF ANY PRODUCTS, SERVICES, INFORMATION, OR OTHER MATERIAL PURCHASED OR OBTAINED BY YOU THROUGH THE SERVICES WILL MEET YOUR EXPECTATIONS AND (e) ANY ERRORS IN THE SOFTWARE WILL BE CORRECTED. (3) ANY MATERIAL DOWNLOADED OR OTHERWISE OBTAINED THROUGH THE USE OF THE SERVICES IS DONE AT YOUR OWN DISCRETION AND RISK AND THAT YOU WILL BE SOLELY RESPONSIBLE FOR ANY DAMAGE TO YOUR COMPUTER SYSTEM OR LOSS OF DATA THAT RESULTS FROM THE DOWNLOAD OF ANY SUCH MATERIAL. (4) NO ADVICE OR INFORMATION, WHETHER ORAL OR WRITTEN, OBTAINED BY YOU FROM 23ANDME OR THROUGH OR FROM THE SERVICES SHALL CREATE ANY WARRANTY NOT EXPRESSLY STATED IN THE TERMS AND SHALL NOT BE RELIED UPON AS MEDICAL ADVICE. (5) YOU SHOULD ALWAYS USE CAUTION WHEN GIVING OUT ANY PERSONALLY IDENTIFYING INFORMATION ABOUT YOURSELF OR THOSE FOR WHOM YOU HAVE LEGAL AUTHORITY. 23ANDME DOES NOT CONTROL OR ENDORSE ANY ACTIONS RESULTING FROM YOUR PARTICIPATION IN THE SERVICES AND, THEREFORE, 23ANDME SPECIFICALLY DISCLAIMS ANY LIABILITY WITH REGARD TO ANY ACTIONS RESULTING FROM YOUR PARTICIPATION IN THE SERVICES. (6) WE MAY REQUEST CERTAIN INFORMATION FROM YOU THAT IS APPLICABLE TO A TRANSACTION, INCLUDING, WITHOUT LIMITATION, CURRENT CREDIT CARD AND OTHER PAYMENT AND SHIPPING INFORMATION. BY PROVIDING US YOUR INFORMATION, YOU EXPRESSLY GRANT US THE RIGHT TO PROVIDE SUCH INFORMATION TO THIRD PARTIES FOR PURPOSES OF FACILITATING THE COMPLETION OF TRANSACTIONS INITIATED BY YOU OR ON YOUR BEHALF.’
- Taken from NZ Terms of Service, last updated 14 November 2025 – same term included in the US and UK domains.
- <https://www.23andme.com/legal/terms-of-service/full-version/>

Framed for Murder by His Own DNA



- This was the experience of Lukis Anderson.
- I highly recommend reading this article in Wired about his experience
- <https://www.wired.com/story/dna-transfer-framed-murder/>

Lukis Anderson was charged for the murder of Raveesh Kumra after his DNA was found on Kumra's fingernails. CARLOS CHAVARRÍA/THE MARSHALL PROJECT

Questions to consider when sharing sensitive data:

- Why am I being asked to share this data?
- Is the collection of this data necessary?
- What is the purpose of the data collection?
- Who will this benefit? You, your family/whanau, wider community?
- Who might this harm? You, your family/whanau, wider community?

And some more:

- Where is the data going to be stored?
- Will it be used to train AI?
- What are the safety mechanisms in place to protect data use?
- What are the security policies in place in relation to this data?
- Do you trust the entity asking for your data?

Things to consider before buying a DNA 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

- Specific legislation to govern the use of genetic data and other sensitive data
- Need for businesses to have been cyber security standards and systems
- Privacy & Security by Design
- Need to improve and harmonise standards
- Better enforcement and compliance with existing law (consumer protection & data protection/privacy, and other applicable law)
- Mandatory codes of conduct
- Model contracts and privacy policies
- Employing the consumer data right in this context
- Regulatory reform
- Compliance reviews/audits

And more

- Industry specific regulators are needed
- Better oversight of what businesses actually do with consumers' data
- Need for consultations and frameworks to be developed in relation to using this data in the courts
- Codes of conduct that are adhered to by industry

Things to consider before buying a DNA test



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

Recent podcast interview with Future Medicine



- Please watch this episode if you are interested in the issues raised in my talk today. Abbigail Hodder interviewed Helen Wallace and I for this episode.
- <https://youtu.be/neS1-c32bg0?si=wrUnZcUWlPWChuq3>

Thank you

Contact information:

Email: andelka.phillips@leicester.ac.uk

Web:

www.andelkamphillips.com

<https://le.ac.uk/people/andelka-phillips>