

Owning Me, Owning You – how private companies acquire rights in our most intimate data

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14th May 2025

Privacy on ***Purpose***

Privacy Week 2025
12 - 16 May

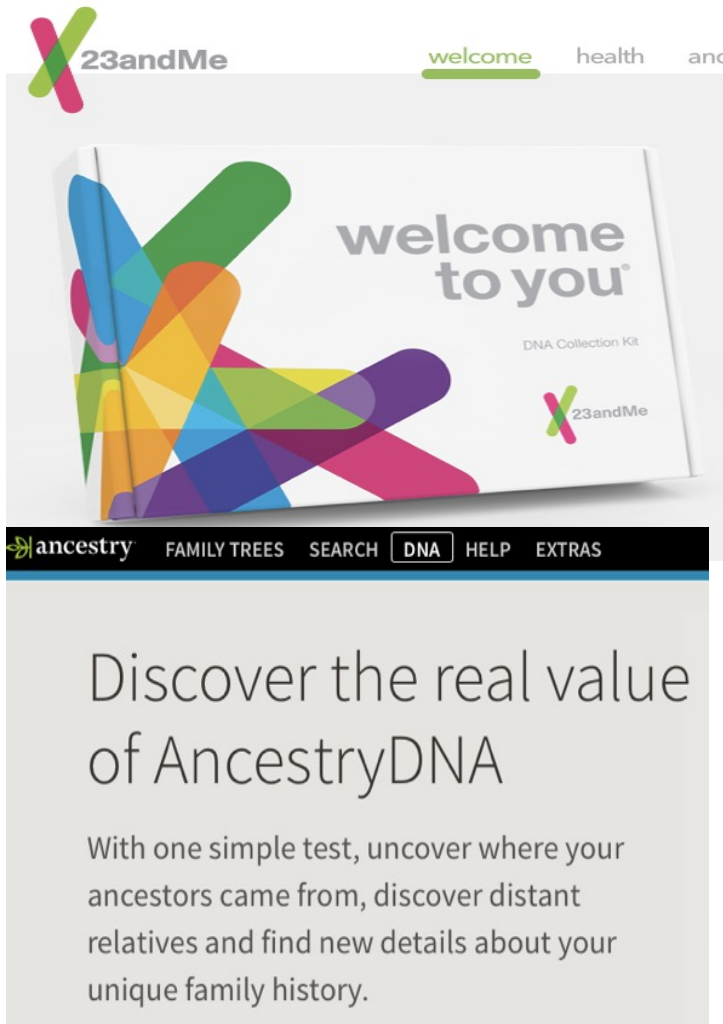
Introduction

- This talk is based on the forthcoming chapter, Andelka M. Phillips, 'Owning me, owning you – How private companies acquire rights in our most intimate data' in forthcoming volume 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) – available for preorder [here](#)

And my related work:

- Andelka M. Phillips, '[Hacking your DNA? Some things to consider before buying a DNA test online](#)' Health Law Blog Sweden (2 March 2024)
- Andelka M. Phillips and Jan Charbonneau, '[In safe hands? The protection of privacy in consumer genomics](#)' Health Law Blog Sweden (23 January 2025)
- AM Phillips, [Buying Your Self on the Internet: Wrap Contracts and Personal Genomics](#) (paperback edition, Edinburgh University Press 2021)

You may have heard of some of these companies



Refresher – 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.
- 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
- You may be aware of the 23andMe data breach and its aftermath

This talk and related work

- Explores the ways that companies acquire rights in our content and data through their contracts in three specific contexts:
 - Personal genomics
 - Wearable fitness monitors
 - And online dating
- This involves considering the intellectual property licenses that businesses acquire from our personal data and user content, which may pose risks to our privacy
- You can think of this as a space where intellectual property and privacy rights collide

Data Breaches and Privacy Risks

Fitbit, Apple user data exposed in breach impacting 61M fitness tracker records

By Heather Landi · Sep 13, 2021 04:21pm

[Link](#)

DNA testing firm discloses data breach affecting 2.1 million people

By Bill Toulas

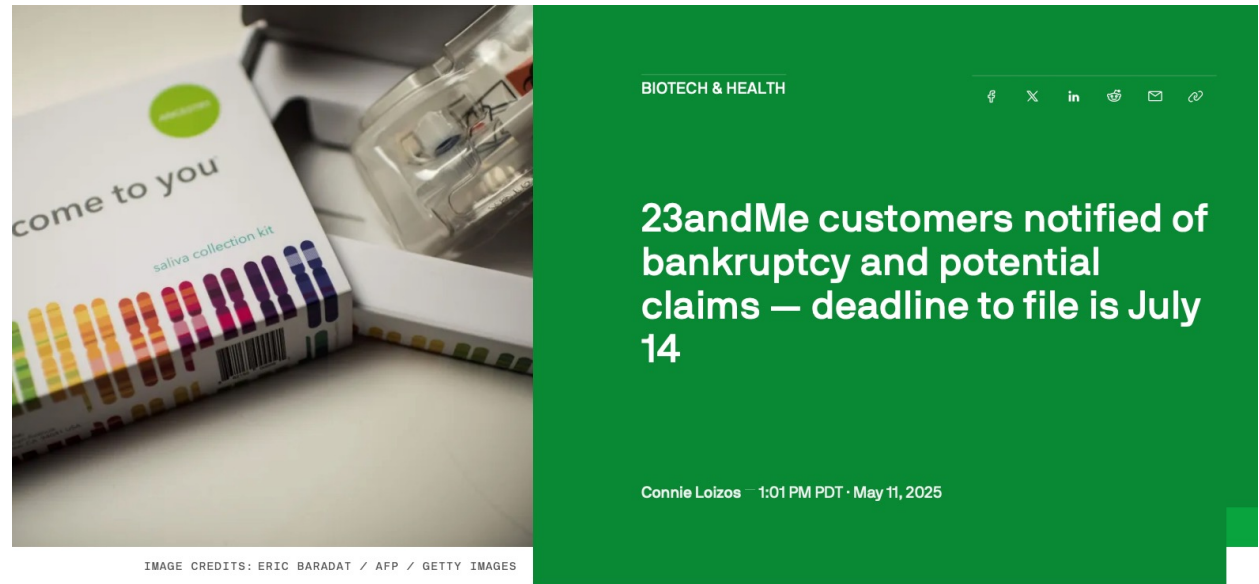
November 30, 2021 08:26 AM 4



[Link](#)

Data breaches and compensation

- Fines may be seen as cost of doing business
- But also individuals may in fact receive very low compensation even where a settlement is large
- We need businesses to do better here.



<https://techcrunch.com/2025/05/11/23andme-customers-notified-of-bankruptcy-and-potential-claims-deadline-to-file-is-july-14/>

THE SWITCH

Use Tinder? Your exact location was exposed for weeks due to a vulnerability.



By [Andrea Peterson](#)

[Link](#)

February 19, 2014 at 4:35 p.m. EST

[Emerging Threats](#)

MyHeritage data breach exposes info of more than 92 million users



Norton

August 08, 2018 • 3 min read

[Link](#)

I asked Tinder for my data. It sent me 800 pages of my deepest, darkest secrets

The dating app knows me better than I do, but these reams of intimate information are just the tip of the iceberg. What if my data is hacked - or sold?

- [Getting your data out of Tinder is really hard - but it shouldn't be](#)

[Link](#)

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



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/>

Statement on 23andMe investigation

Date **24 March 2025**

Type **Statement**

Stephen Bonner, ICO Deputy Commissioner - Regulatory Supervision, said:

"Genetic information is among the most sensitive personal data that a person can entrust to a company and organisations handling such data are required to uphold a very high standard of security and governance in accordance with the UK GDPR.

"The ICO and the Office of the Privacy Commissioner of Canada have been jointly investigating the data breach that 23andMe first reported to us in October 2023. Earlier this month, we issued 23andMe with our provisional findings, a notice of intent to fine £4.59m and a preliminary enforcement notice. We would stress these findings are provisional and, as with all preliminary findings, are subject to representations from 23andMe including in relation to affordability considerations. The ICO will carefully consider any representations made before taking a final decision.

"We are aware that 23andMe has filed for Chapter 11 bankruptcy in the US to facilitate a sale process. We are monitoring the situation closely and are in contact with the company. As a matter of UK law, the protections and restrictions of the UK GDPR continue to apply and 23andMe remains under an obligation to protect the personal information of its customers."

<https://ico.org.uk/about-the-ico/media-centre/news-and-blogs/2025/03/statement-on-23andme-investigation/>

23andMe Settles Data Breach Lawsuit for \$30 Million

Posted By Steve Alder on Sep 16, 2024

A settlement had previously been agreed in principle to resolve a 23andMe HIPAA data breach lawsuit and now the terms have been finalized. 23andMe has agreed to pay \$30 million to settle the consolidated class action lawsuit – *In re 23andMe Inc Customer Data Security Breach Litigation* – and received preliminary approval for the settlement in federal court in San Francisco on Thursday. The settlement still requires final approval from a federal court judge.

<https://www.hipaajournal.com/23andme-class-action-data-breach-settlement/>

Privacy Policies & Electronic (Wrap) Contracts are everywhere online

- How many contracts and privacy policies have you encountered online?
- How many of these have you actually 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.

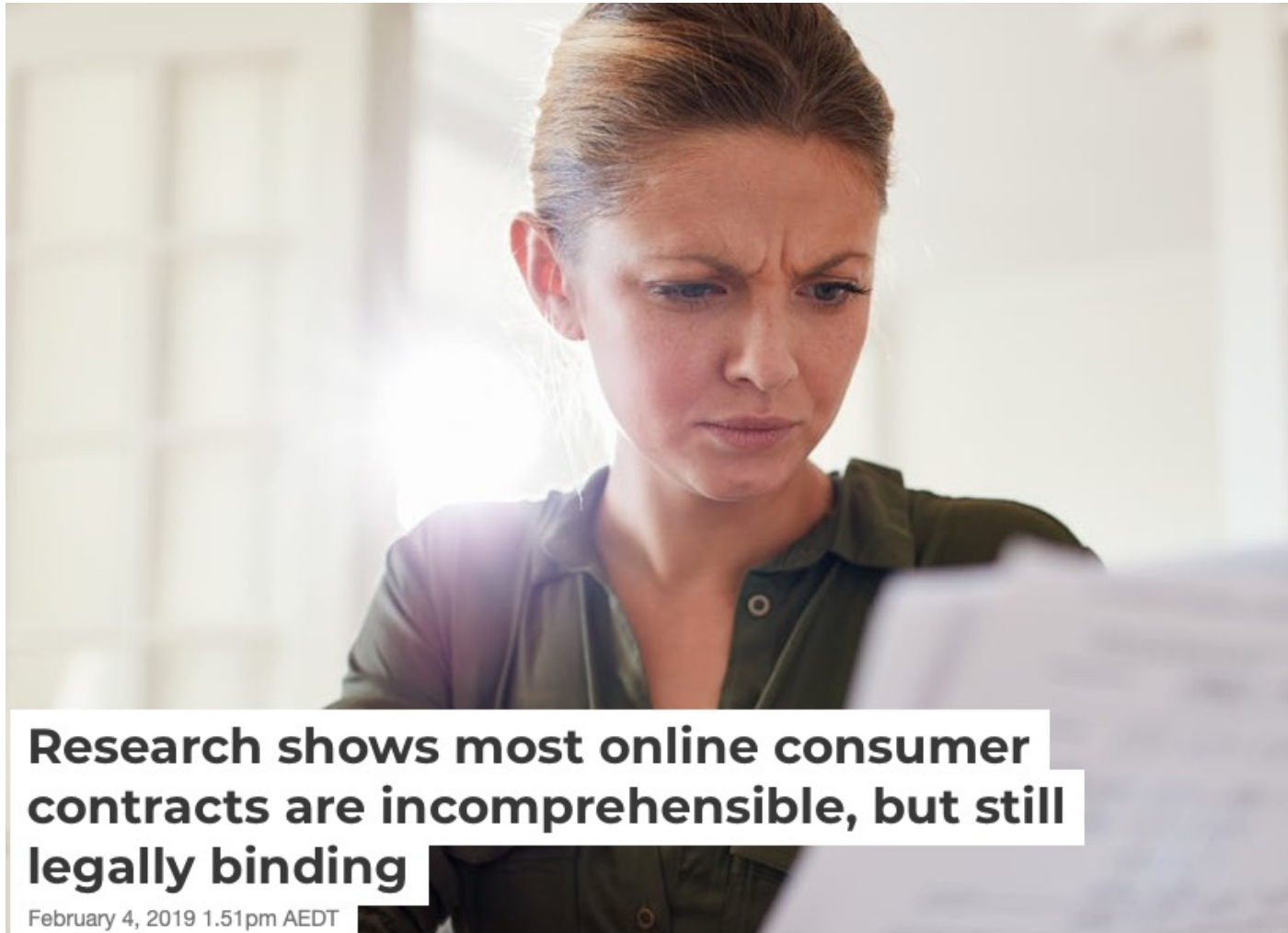
Norwegian Consumer Council

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

APPFAIL

Threats to Consumers in Mobile Apps

March, 2016



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>

Dr Andelka M. Phillips, 14 May 2025

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’

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

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

Owning Me, Owning You - examples

Example from 23andMe's Terms of Service

- 'You give 23andMe, its affiliated companies, sublicensees and successors and assignees a perpetual, irrevocable, worldwide, royalty-free, and non-exclusive license to host, reproduce, adapt, modify, translate, publish, publicly perform, store, publicly display, distribute, reproduce, edit, reformat, and create derivative works from any User Content that you submit, post, or display on or through the Services. This license is fully-paid and royalty free, meaning we do not owe you anything else in connection with our use of your User Content. You acknowledge and agree that this license includes a right for 23andMe to make such User Content available to other companies, organizations, or individuals with whom 23andMe has relationships, and to use such User Content in connection with the provision of those services.'
- 23andMe, "Terms of Service" US Version (last updated 30 November 2023), online: <https://www.23andme.com/legal/terms-of-service/#licensing-ip-rights> – international version contains the same clause

Let's think about what this means?

- the definition of what constitutes 'User Content' does specifically exclude 'genetic or health information'.
- However, 'User Content' does cover basically any other thing that a consumer might share, including their messages, photographs, information, text and video.
- Also, this applies to things that are shared both privately and publicly.
- Licence is framed as irrevocable
- Finally – this licence is not only for 23andMe, but 23andMe's successors and affiliates

Example from Garmin's Terms of Use

- 'The Site may provide the opportunity for users to submit content ("User Submissions") for viewing by one or more Site users, such as a message board, chat or comment feature, or forum.'
- 'By submitting User Submissions to the Site, you grant, or warrant that the owner of such material has expressly granted, Garmin the royalty-free, perpetual, irrevocable, non-exclusive right and license to use, reproduce, modify, adapt, publish, translate, and distribute such material (in whole or in part) worldwide and/or to incorporate it in other works in any form, media, or technology now known or hereafter developed for the full term of any copyright or other rights that may exist in such material. You will be solely liable for any damage resulting from any defamation, infringement of copyrights, proprietary rights, or any other harm or claim resulting from a User Submission.'
- Garmin, "Terms of Use" US Version (effective date 17 February 2024) <https://www.garmin.com/en-US/legal/terms-of-use/#section3-1>; Note that the NZ Version includes the same clause. Garmin, "Terms of Use" NZ Version (effective date 17 February 2024), online: <https://www.garmin.com/en-NZ/legal/terms-of-use/#section3-1>

Let's think about what this means?

- Very similar to the 23andMe clause
- Irrevocable
- Covers a very broad range of potential formats, both now known and covering future technologies

Example from Fitbit's Terms of Service

- 'Fitbit may enable you to post, upload, store, share, send, or display photos, images, video, data, text, music, exercise regimens, food logs, recipes, comments, and other information and content ("Your Content") to and via the Fitbit Service. You retain all rights to Your Content that you post to the Fitbit Service. By making Your Content available on or through the Fitbit Service you hereby grant to Fitbit a non-exclusive, transferable, sublicensable, worldwide, royalty-free license to use, copy, modify, publicly display, publicly perform, reproduce, translate, create derivative works from, and distribute Your Content, in whole or in part, including your name and likeness, in any media. The rights you grant us in this Section 5 are only for the limited purpose of offering and improving the Fitbit Service.'
- Fitbit, "Terms of Service" (last updated 2 February 2024), online: <https://www.fitbit.com/global/nz/legal/terms-of-service>

Let's think about this clause

- Very similar language to Garmin and 23andMe
- It also allows for using the consumer's 'name and likeness'

Example from Match.com's Terms of Use

- **You own all of the content you provide to Match, but you also grant us the right to use Your Content as provided in this Agreement.**
- By creating an account, you grant to Match a worldwide, perpetual, transferable, sub-licensable, royalty-free right and license to host, store, use, copy, display, reproduce, adapt, edit, publish, translate, modify, reformat, incorporate into other works, advertise, distribute and otherwise make available to the general public Your Content, including any information you authorize us to access from Facebook or other third-party sources (if applicable), in whole or in part, and in any way and in any format or medium currently known or developed in the future. Match's license to Your Content shall be non-exclusive, except that Match's license shall be exclusive with respect to derivative works created through use of our Services. For example, Match would have an exclusive license to screenshots of our Services that include Your Content...
- Match.com, "Terms of Use" New Zealand Version (effective 28 February 2022), online: <https://nz.match.com/masp/en-au/terms>

Let's think about this clause

- Note the similarity in language
- and the scope of this term.
- It covers broad range of uses capturing both known and future technology.
- Lastly, it also includes a right to use screenshots of a user's content.
- Match also owns Tinder and terms are very similar

Thinking about sensitive data

- Certain forms of data may be unique identifiers
- 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.

Key takeaways

- As a consumer wanting to use these services:
 - Please do some research first
 - Think about your level of comfort with different types of sharing of data
 - Think about how you would feel if something goes wrong
- If you are in a business handling personal & sensitive data
 - Please embrace privacy & security by design
 - Think about the content of your contracts & policies
 - Think about what you as a business really need to do with data
 - Consider offering privacy enhancing services

Suggestions for reform

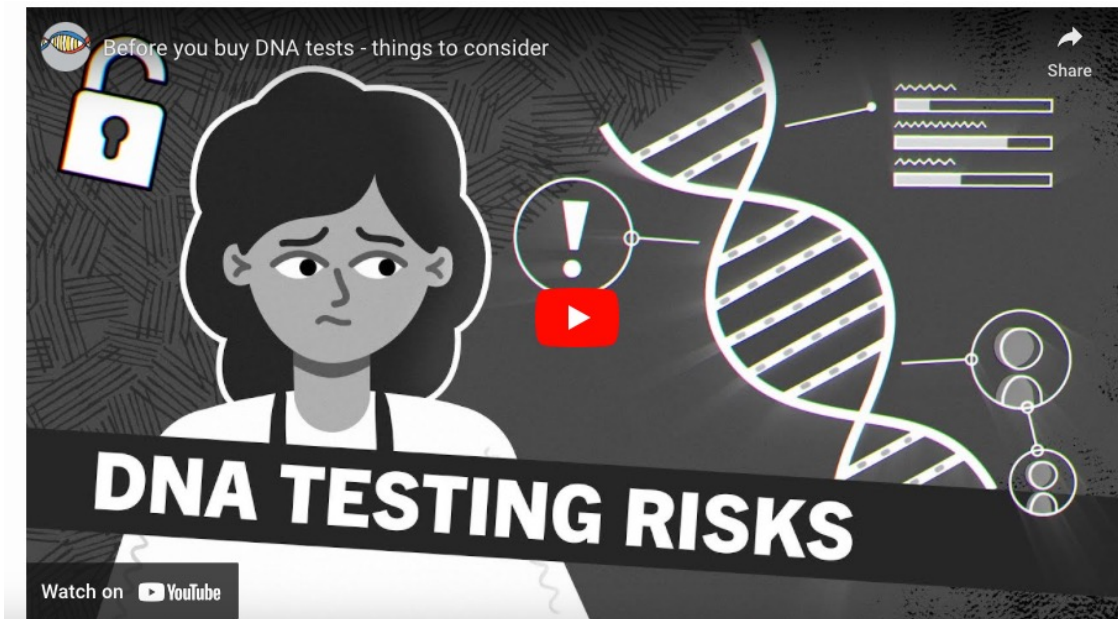
- Need to improve and harmonise standards
- Better enforcement & compliance with existing law (privacy/data protection, consumer protection, and other applicable law).
- Need for collaboration between regulators internationally.
- Need for improved transparency
- Regulatory reform – amendments to existing legislation & industry specific legislation where necessary
- Compliance reviews/audits

Further suggestions

- Need to improve cyber security across industries
- More oversight of what businesses actually do with consumers' data – what happens when companies merge
- 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

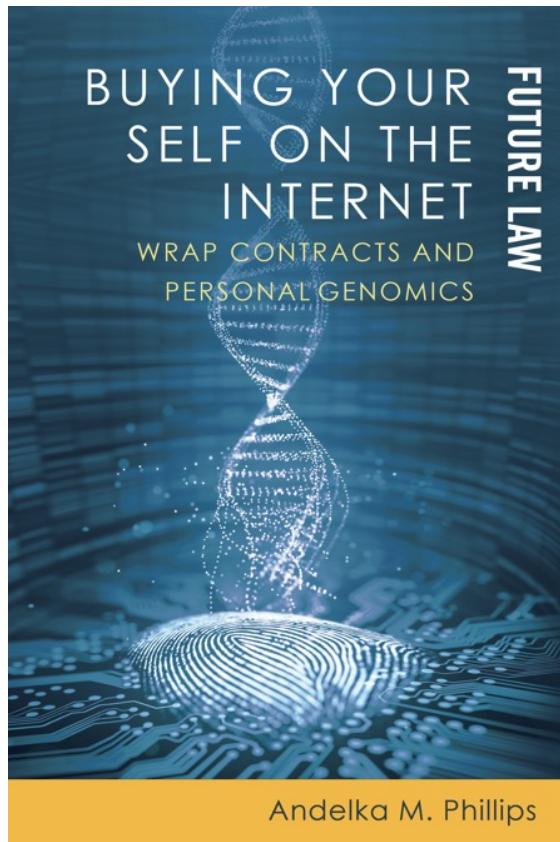
If you are interested, please have a look at this video –

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.

Related publications



- AM Phillips, *Buying Your Self on the Internet: Wrap Contracts and Personal Genomics* (Edinburgh University Press 2019) [JSTOR Link](#) & publisher [Link](#)
- Andelka M. Phillips and Jan Charbonneau, 'In safe hands? The protection of privacy in consumer genomics' Health Law Blog Sweden (23 January 2025) [Link](#)
- AM Phillips, 'Hacking your DNA? Some things to consider before buying a DNA test online' Health Law Blog Sweden (2 March 2024) [Link](#)
- 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.law.ox.ac.uk/people/andelka-phillips>
- <https://www.bioethics.ugent.be/our-people/andelkamphillips/>

