

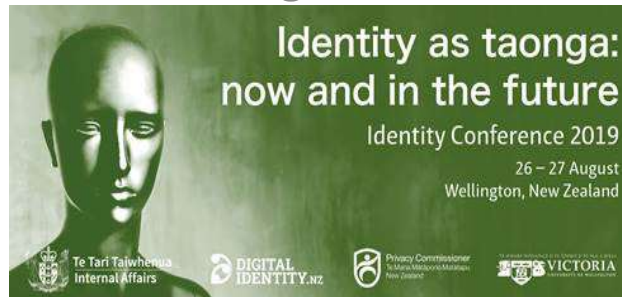
Personal Genomics and Identity

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26th August 2019.



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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



Heredity or hoax?

How dog DNA helped uncover a suspected Indian status scam

By Jorge Barrera and Tiffany Foxcroft

June 13, 2018

When Louis Côté became suspicious of a Toronto-based laboratory that tests people's DNA to determine their ancestry, he decided to try an experiment by submitting a sample from his girlfriend's dog for analysis.

According to the results, Côté shares more than a friendship with Snoopy the chihuahua; they share the exact same Indigenous ancestry.

"I thought it was a joke," Côté said. "The company is fooling people ... the tests are no good."

A subsequent CBC News investigation has found there are not only concerns about the accuracy of the DNA tests but also about the possible fraudulent use of cards resembling certificates of Indian status to secure tax exemptions the holders aren't entitled to.

<https://newsinteractives.cbc.ca/longform/dna-ancestry-test>

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

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

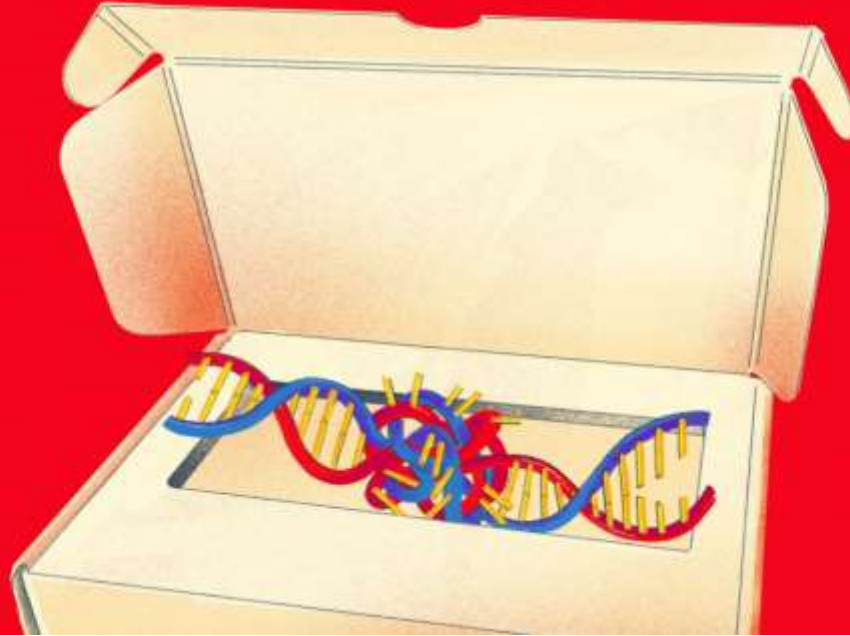
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Tyson Whiting

<https://www.vox.com/2014/9/9/5975653/with-genetic-testing-i-gave-my-parents-the-gift-of-divorce-23andme>

How DNA Testing Botched My Family's Heritage, and Probably Yours, Too



<https://gizmodo.com/how-dna-testing-botched-my-family-heritage-and-probab-1820932637>

Data Breaches

Ancestry.com suffers big data leak - 300,000 user credentials exposed

By Francis Navarro, Komando.com

34,530



<https://www.komando.com/happening-now/435921/ancestry-com-suffers-big-data-leak-300000-user-credentials-exposed>

MyHeritage breach leaks millions of account details

Your DNA data is safe, though... for now

By Makana Kelly | Jun 5, 2018, 2:08pm EDT

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<https://www.theverge.com/2018/6/5/17430146/dna-myheritage-ancestry-accounts-compromised-hack-breach>

FamilyTreeDNA Admits to Sharing Genetic Data With F.B.I.



FamilyTreeDNA, an at-home DNA testing company, apologized for failing to disclose it was sharing genetic information with the F.B.I. to help solve rapes and murders. Some of the site's users felt the company had betrayed them.
Sue Orocki/Associated Press

By Matthew Haag

<https://www.nytimes.com/2019/02/04/business/family-tree-dna-fbi.html>

GEDmatch reverses course

by Judy G. Russell | May 19, 2019 | DNA | 34 comments

Law enforcement matching now opt-in only

Informed consent is the essential underpinning of ethical DNA testing and results-sharing. All persons who test have the right to make their own individual choices about testing and about the uses to which their DNA results will be put — including its use by law enforcement to fish for suspects in criminal investigations.

And, late last night, the third-party DNA tools site GEDmatch gave its users that right back.

In a stunning reversal of course, GEDmatch updated its terms of use late last night to change its entire system for allowing law enforcement to access its database to match crime scene test kits to kits uploaded by genealogical users: only those persons who affirmatively opt in to that use will be matched to police-uploaded kits.



<https://www.legalgenealogist.com/2019/05/19/gedmatch-reverses-course>

Golden State Killer suspect was tracked down through genealogy website GEDmatch

A relative's genetic profile led police to the suspect

By Rachel Becker | @RA_Becks | Apr 26, 2018, 10:51pm EDT



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[https://www.theverge.com/2018/4/26/17288532/golden-state-killer-east-area-
rapist-genealogy-websites-dna-genetic-investigation](https://www.theverge.com/2018/4/26/17288532/golden-state-killer-east-area-rapist-genealogy-websites-dna-genetic-investigation)

Orig3n and ZhongAn, China's Largest E-Insurer Announce Partnership on Health Tech

CISION PR Newswire August 1, 2018

BOSTON and SHANGHAI, July 31, 2018 /PRNewswire/ -- Orig3n, Inc., a Boston-based biotech company pioneering the future of health through genetics and regenerative medicine, and ZhongAn Online P&C Insurance Co., Ltd. (6060.HK), the first and largest online-only insurance company in China, today announced a new partnership to bring health tech solutions to Chinese consumers.

<https://finance.yahoo.com/news/orig3n-zhongan-chinas-largest-e-153400807.html>

Related publications

- Andelka M. Phillips, 'Buying Your Genetic Self Online: Pitfalls and Potential Reforms in DNA Testing' (May/June 2019) IEEE Security and Privacy 77-81 doi:10.1109/MSEC.2019.2904128 – the accepted version is also available on the Privacy Foundation's website <https://www.privacyfoundation.nz/buying-your-genetic-self-online/>
- Andelka M. Phillips, 'Genetics goes online – privacy in the world of personal genomics' Privacy Laws & Business International Report (October 2018) – this follows on from my session at the Privacy Laws & Business 31st Annual International Conference Navigating GDPR: The art of the possible (2-4 July 2018, St. John's College, Cambridge). https://www.privacylaws.com/Publications/int/PLB_International_Issues/PLB-International-Issue-155/
- Andelka M. Phillips, 'Reading the Fine Print When Buying Your Genetic Self Online: Direct-to-Consumer Genetic Testing Terms and Conditions' (2017) 36(3) New Genetics and Society 273-295 <http://dx.doi.org/10.1080/14636778.2017.1352468>

Related publications

- Andelka M. Phillips, 'Only a Click Away – DTC Genetics for Ancestry, Health, Love... and More: A View of the Business and Regulatory Landscape' (March 2016) 8 Applied & Translational Genomics 16-22.
<http://www.sciencedirect.com/science/article/pii/S2212066116300011>
- Andelka Phillips, 'Genomic Privacy and Direct-to-Consumer Genetics – Big Consumer Genetic Data – What's in that Contract?' (presented at GenoPri'15 (The 2nd Workshop on Genome Privacy and Security) and published as part of IEEE Conference Proceedings 2015)
<http://www.genopri.org/uploads/3/9/9/9/39999711/9933a060.pdf>
- Dataset available via Zenodo.
https://zenodo.org/record/1183565#.W_9gpy1L1TY

Buying your Self on the Internet

Wrap Contracts and Personal Genomics

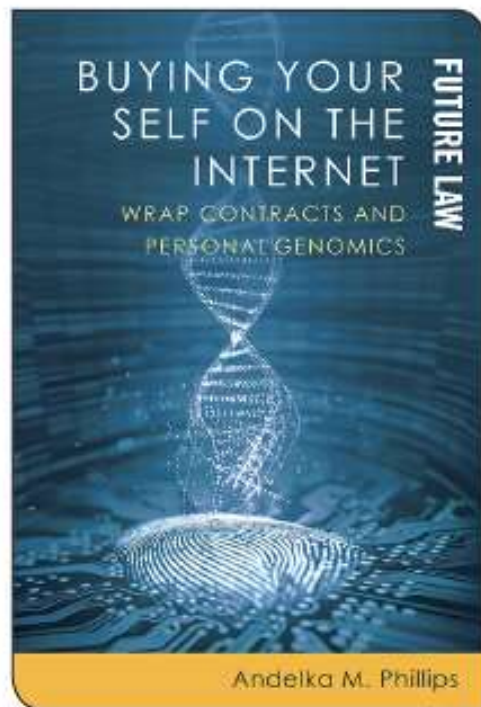
Andelka M. Phillips

Considering ordering a genetic test online?

Did you stop to read the fine print?

Most of us never consider the contracts we enter into online. We click 'Agree' and move on. This book provides an introduction to the world of personal genomics and examines the rise of the direct-to-consumer (DTC) genetic testing industry and its use of 'wrap' contracts. It explores the different types of tests available and the issues that this industry raises for law and for society.

Hardback £85 | \$130 July 2019 312 pages
ISBN: 9781474422598 Also available in ebook



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Dr Andelka M. Phillips, 26 August 2019



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