

Written evidence submitted by Dr Andelka Phillips (CGN0025)

I have also submitted two of my recent articles,¹ but below is my written submission of suggestions for regulatory reform of Commercial Genomics.

I am a legal academic, who has been researching the regulation of this industry for almost a decade. I am now based in New Zealand, but completed my doctorate in law on this subject at Oxford University and have also worked at Trinity College Dublin. I also have a forthcoming book on the industry and its regulation.² Below I have set out recommendations for improving regulation of the industry both in the short and long term.³

Short term strategies for improving regulation:

- There is a pressing need to provide the public with access to more independent informational resources to assist them in making informed decisions about whether or not to utilise commercial genomics services. Data protection authorities and privacy regulators as well as consumer regulators could release statements in relation to the industry. The Office of the Canadian Privacy Commissioner has already begun to take steps in this direction. It has released a number of documents in relation to this industry, including recommendations for questions that consumers could ask companies, and questions that they should ask themselves when considering purchasing a test.⁴ This example could provide a useful model for other regulators exploring these issues.

¹ 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>>

² Andelka M Phillips, *Buying Your Self on the Internet: Wrap Contracts and Personal Genomics* (forthcoming, Edinburgh University Press 2019) <<https://edinburghuniversitypress.com/book-buying-your-self-on-the-internet-hb.html>> ; and Andelka M Phillips, 'Only a Click Away – DTC Genetics for Ancestry, Health, Love... and More: A View of the Business and Regulatory Landscape' (2016) 8 *Applied & Translational Genomics* 16-22 <<https://doi.org/10.1016/j.atg.2016.01.001>>

³ Many of these recommendations are also made in a forthcoming article, Andelka M. Phillips, 'Buying Your Genetic Self Online: Pitfalls and Potential Reforms in DNA Testing' *IEEE Security & Privacy* (forthcoming May/June 2019)

⁴ Office of the Canadian Privacy Commissioner, *Policy statement on the collection, use and disclosure of genetic test results* (OPC, updated December 2017) <https://www.priv.gc.ca/en/privacy-topics/health-genetic-and-other-body-information/s-d_140710/> last accessed 27 October 2018; Office of the Canadian Privacy Commissioner, 'Direct-to-consumer genetic testing and privacy' (OPC, updated December 2017) <https://www.priv.gc.ca/en/privacy-topics/health-genetic-and-other-body-information/02_05_d_69_gen/> last accessed 27 October 2018.

- Given the recent use of genetic databases⁵ and for example the collaboration between FamilyTreeDNA and the US FBI to investigate violent crime, there is a need for much more public debate about secondary use of such databases.⁶
- Existing regulators should also consider developing industry codes of conduct and model privacy policies and consumer contracts. One potential foundation for such a code is the Future of Privacy Forum's paper "Privacy Best Practices for Consumer Genetic Testing Services" (June 2018), which was developed in collaboration with some prominent DTC companies.⁷ This document makes a number of positive commitments in relation to privacy, but it is voluntary and it remains to be seen how businesses will adhere to this. Unlike the Future of Privacy Forum paper, though, any code should make it clear that American companies selling genetic tests to consumers based in in the UK should be complying with the Data Protection Act 2018 and the GDPR and companies selling tests to EU consumers should also be complying with the GDPR. As the GDPR is exerting a global influence, companies may also have to comply with similar legal requirements when selling tests to consumers based in other countries as well.
- Another model is to make codes of conduct mandatory for the industry to follow.
- Businesses should rethink their drafting of contracts and privacy policies. In relation to contracts, clauses that significantly limit consumers' rights should be avoided. For example, if businesses wish to be compliant with the Data Protection Act (and GDPR) and applicable consumer protection legislation, such as the UK's Consumer Rights Act 2015 then they should not include clauses that allow them to change their terms at any time without notice to the consumer. This

⁵ Rachel Becker, 'Golden State Killer suspect was tracked down through genealogy website GEDmatch' *The Verge* (26 April 2018) <<https://www.theverge.com/2018/4/26/17288532/golden-state-killer-east-area-rapist-genealogy-websites-dna-genetic-investigation>> last accessed 12 December 2018; and Tina Hesman Saey, 'Why using genetic genealogy to solve crimes could pose problems' *ScienceNews* (7 June 2018) <<https://www.sciencenews.org/article/why-police-using-genetic-genealogy-solve-crimes-poses-problems?mode=pick&context=2782&tgt=nr>> last accessed 24 October 2018; Megan Molteni, 'The Key To Cracking Cold Cases Might Be Genealogy Sites' *Wired* (1 June 2018) <<https://www.wired.com/story/police-will-crack-a-lot-more-cold-cases-with-dna/>> ; GEDmatch, <<https://www.gedmatch.com/tos.htm>> accessed 2 August 2018.

⁶ Matthew Haag, 'FamilyTreeDNA Admits to Sharing Genetic Data With F.B.I.' *The New York Times* (4 February 2019) <<https://www.nytimes.com/2019/02/04/business/family-tree-dna-fbi.html>> accessed 12 February 2019.

⁷ Future of Privacy Forum, *Privacy Best Practices for Consumer Genetic Testing Services* (31 July 2018) <<https://fpf.org/wp-content/uploads/2018/07/Privacy-Best-Practices-for-Consumer-Genetic-Testing-Services-FINAL.pdf>> last accessed 24 October 2018.

type of clause is particularly problematic, as contracts and privacy policies are often linked together and it could allow for significant changes to a privacy policy.

- Businesses should also think about their interface design. Given the sensitive nature of genetic data and the complex nature of some health test results, consumers should not be rushed into making a purchase. Putting speed bumps into the process, which encourage reflection and allow consumers to change their minds could help to achieve compliance with the GDPR. It would be beneficial for businesses to allow for a cooling off period as well in between purchase and processing of the sample.
- Businesses should also improve their practices in relation to deletion and destruction of physical samples and data. It should be possible for any company performing a genetic test to provide their consumers with the option of deleting the data and destroying the sample after sending the consumer their test results.
- Businesses should also keep in mind the GDPR's principles in relation to data processing. In the context of DTC, adhering to the data minimisation principle could be particularly beneficial.
- At the national level, privacy and data protection regulators as well as consumer protection regulators should play a role in improving industry governance. Compliance reviews of privacy policies, contracts, and personal data practices, particularly in relation to security practice would all be beneficial for improving industry governance.

Longer term strategies:

- We need more specific oversight of the industry in order to improve standards and ensure the protection of privacy and consumer rights more generally. One possibility is the creation of new regulatory bodies with a mandate to regulate all businesses that handle genetic data. This could draw upon existing models of privacy regulators and financial services regulators and in some countries, this could be a new body that was under the oversight of the privacy regulator, such as the ICO.
- Tests of more dubious validity, such as surreptitious tests and child talent should be banned and regulators should help to alert the public about the most problematic services. In the UK, the Human Tissue Act makes it an offence to analyse DNA without appropriate consent and it is likely that any company offering surreptitious tests to UK consumers is likely to be in breach of this.

- New legislation dealing more specifically with individual's rights in genetic data is needed. The recent Canadian Genetic Non-Discrimination Act could provide a useful model for other countries considering how to strengthen the rights of citizens in their genetic data.
- New industry specific legislation should also be introduced at a national level and international collaboration to develop more universal standards that could be followed globally could also help consumers given the international nature of these services.

Thank you for your consideration.

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