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> YOUR DNA IS ONLY A CLICK AWAY - PERSONAL GENOMICS, PRIVACY, SECURITY, AND A CALL FOR REFORM

Your DNA is only a click away - Personal Genomics, Privacy, Security, and a call for reform

Andelka Phillips (Te Piringa – Faculty of Law, University of Waikato)

15
MAY 14:00 15th May 2019 (Trinity Term 2019)

Dr Phillips will discuss her ongoing research on the direct-to-consumer genetic testing (DTC) industry, drawing upon her book, *Buying Your Self on the Internet: Wrap Contracts and Personal Genomics*, which will be published in June 2019 by Edinburgh University Press, as part of their Future Law series.

We have all grown accustomed to clicking 'I Agree' online, often without reading Terms and Conditions or Privacy Policies, but as more new services handling sensitive data are coming to market this lack of reading is problematic. The DTC industry has developed over the last two decades. It has created a market for DNA tests as consumer services, bringing them outside the clinic and into the domestic space. Individuals in this space can now be viewed as consumers, rather than patients and these services pose challenges for existing regulation. Genetic data is also sensitive data. It can serve as a unique identifier for individuals, it can also be used to trace family members, and it can be used for a wide range of secondary research purposes, meaning that there are significant privacy risks to consider in this context.

The industry offers tests for diverse purposes. These range from tests for health conditions to the increasingly popular category of ancestry testing, as well as tests for genetic relatedness (most commonly paternity), as well as more dubious tests for child talent and 'infidelity' or matchmaking.

This talk will provide an introduction to the DTC industry and the issues these services raise for law and society more generally. This will include an overview of the variety of tests available, discussion of the contracts used by DTC companies, as well as the privacy issues these services raise.

The book uses the example of DTC genetic testing companies using wrap contracts as their dominant means of governance to show the challenges that disruptive technologies pose for societies and for regulation. The book:

- Reviews 71 wrap contracts used by DTC companies providing health testing
- Explores broader issues with online contracting
- Sets an agenda for improving regulation and the online contracting environment

Speaker bio


Dr Phillips is a Senior Lecturer at Te Piringa Faculty of Law and a Research Associate with the University of Oxford's Centre for Health, Law and Emerging Technologies (HeLEX). Her recent research has focused on the regulation of direct-to-consumer genetic tests, examining the industry's use of wrap contracts (browsewrap and clickwrap). This is the subject of her forthcoming book entitled *Buying Your Self on the Internet: Wrap Contracts and Personal Genomics*, which will be published by Edinburgh University Press as part of its Future Law series in June 2019. She is also co-editing with Professor Jonathan Herring and Dr Thana C de Campos *Philosophical Foundations of Medical Law*, which will be published as part of Oxford University Press' *Philosophical Foundations of Law* series in 2019. Andelka was formerly the Ussher Assistant Professor in Information Technology Law and the Convenor of the Technology, Law and Society Research Group in the Law School at Trinity College Dublin, the University of Dublin. She has also taught at the University of Oxford and the University of Auckland. She completed her doctoral degree at Oxford and her doctoral research examined the use of online wrap contracts (clickwrap and browsewrap) and the protection of consumers' rights in their genetic information in the context of direct-to-consumer (DTC) genetic testing. While at Oxford, she was the General Editor of the *Oxford University Commonwealth Law Journal* and also convened the *Oxford Medical Law and Ethics Discussion Group* and the *Oxford Privacy Information Law and Society Discussion Group*.

<https://www.waikato.ac.nz/staff-profiles/people/aphillip/>

<http://www.andelkamphillips.com>

<https://edinburghuniversitypress.com/book-buying-your-self-on-the-internet-hb.html>

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