

3 May 2019, Friday, 2pm – 3.30pm National University of Singapore, Bukit Timah Campus Centre for International Law, 469A Bukit Timah Road Tower Block, #09-01, Singapore 259770 CIL BOARDROOM

Reading the Fine Print: An Introduction to the World of Personal Genomics and Wrap Contracts by Dr Andelka M Phillips

Admission is free. To register, please click here.

INTRODUCTION 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.

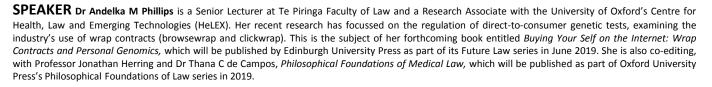
The DTC industry has developed over the last two decades. It has created a market for DNA tests as consumer services, bringing them outside the clinic and into the domestic space. Individuals in this space can now be viewed as consumers, rather than patients, and these services pose challenges for existing regulations. Genetic data is also sensitive data. It can serve as a unique identifier for individuals, and it can be used to trace family members and also for a wide range of secondary research purposes. Hence 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, tests for genetic relatedness (most commonly paternity), and 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, and the privacy issues these services raise.

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

- reviews 71 wrap contracts used by DTC companies providing health testing,
- explores broader issues with online contracting, and
- sets an agenda for improving regulation and the online contracting environment.



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 doctorate 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 Commonweath Law Journal* and also convened the Oxford Medical Law and Ethics Discussion Group and the Oxford Privacy Information Law and Society Discussion Group.

ABOUT THE CENTRE FOR INTERNATIONAL LAW

The Centre for International Law (CIL) is based at the Bukit Timah campus of the National University of Singapore. CIL's mission is to enable Singapore and the Asia-Pacific region to play a more significant role in the promotion and development of international law and policy. The Centre's vision is to become the region's intellectual hub and thought leader for research on and teaching of international law and policy. The director of CIL is Professor Lucy Reed. For more information, please visit the CIL website at www.cil.nus.edu.go contact LI at <u>cl.linfo</u>@miss.edu.sg.Centre for international Law, National University of Singapore, Bukit Timah Campus, Tower Block, 809-01, 469A Bukit Timah Road, Singapore 25970



