

Privacy, Data Protection and Data-Sharing in Biomedical Research

Part II of one day Symposium

Wednesday, 11 April 2018

2:00pm – 5:00pm

Academic Conference Room,
11/F, Cheng Yu Tung Tower,

Faculty of Law, The University of Hong Kong



Programme Rundown

Time	Events
1:45pm – 2:05pm	Registration
2:05pm – 2:15pm	Welcome address Mr Eric TSE Assistant Privacy Commissioner for Personal Data, Hong Kong SAR
2:15pm – 2:45 pm	Lecture 1: "What is Privacy? (What is Data Protection?)" <i>For as long as privacy has been the focus of academic attention, it has been criticized as an ill-defined concept, and for as long as scholars have tried to clarify the nature of privacy, their definitions have been rejected as too broad, too narrow, or both. In light of this history, privacy scholars are increasingly concluding that a unified account of privacy is unattainable. I will argue that this conclusion is mistaken and arises from a basic category error, in which descriptive and normative theories of privacy are conflated. When privacy losses and privacy violations are instead differentiated and analyzed independently, it becomes clear that a unified account of privacy is attainable, but that privacy rights are limited in ways that have gone unrecognized.</i> Speaker: Dr Jeff Skopek, Lecturer in Medical Law, Ethics and Policy, University of Cambridge
2:45pm – 3:15 pm	Lecture 2: Big Data and Medical Health Research <i>The increasing popular use of mobile devices, wearables and apps to monitor one's health, lifestyle and fitness has set a new trend known as mobile health - mHealth. In 2016, there were 165,000 health-related apps which run on two main smartphone operating systems. The mHealth ecosystem includes (1) self-tracking apps and appliances that used to monitor wearers' physical fitness e.g. Fitbit, Jawbone and Apple Watch; (2) prescribed apps and devices required by medical practitioners or authorities to be worn by patients e.g. UK's GDM-health project on diabetes patients; and (3) self-volunteered participation in large scale</i>

	<p><i>population study for health (e.g. Apple ResearchKit and Google's Baseline).</i></p> <p><i>We are often amazed by the power of mHealth gadgets but we seldom question how the health data are streamed and analysed. Not only are we being confronted with our own data on steps, sleep, stress, dreams, fertility or even sex, we may have let others getting insights on ourselves 24 hours a day. While mHealth has brought convenience and has lowered the cost of healthcare, the increasing individualization and consumerism in healthcare has also transformed our notion on consent, and how data are collected, used and shared. Attempts have been made in the European Union and the United States to set out privacy and security guideless in this area of mHealth. This study provides an overview of the privacy issues on mHealth and identifies the legal gaps in regulation. What is needed is an appropriate legal response.</i></p> <p>Speaker: Professor Anne Cheung, Professor, Faculty of Law, the University of Hong Kong</p>
3:15pm – 3:30pm	Break
3:30pm – 4:00pm	<p>Lecture 3: Going Global? The General Data Protection Regulation and Transborder Data Flow in an Interconnected World</p> <p><i>The Snowden revelations catapulted restrictions on the flow of personal data overseas into the very centre of the data protection debate and the General Data Protection Regulations sets out a much tougher regulatory approach here than was previously the norm in many EU Member States (including the UK). Going forward, transfers to a new controller or processor based overseas will only be legitimate if certain strict conditions are met, such as a European Commission decision that the jurisdiction in question provides “adequate”/“essentially equivalent” protection or the appropriate use of standard contractual clauses. It is nevertheless important to keep in mind that these rules are not ends in themselves but rather meant to be instrumental means to securing a high, yet also contextual, level of data protection. In a ubiquitously connected world, this may necessitate some rethinking of what we mean by a “transfer” of personal data. It will also require active work by data protection authorities to help craft solutions which safeguard data subjects whilst also enabling other positive goals to be fulfilled including satisfying “the legitimate expectations of society for an increase of knowledge” (GDPR, recital 113).</i></p> <p>Speaker: Dr David Erdos, Deputy Director, Centre for Intellectual Property and Information Law, University Senior Lecturer in Law and the Open Society, Faculty of Law, WYNG Fellow in Law, Trinity Hall University of Cambridge</p>
4:00pm – 4:30pm	<p>Lecture 4: Privacy and Genomic Data Sharing in China</p> <p><i>The study reviews the privacy implications of recent regulatory developments in China regarding the sharing of genomic data. The collection, storage and sharing of Chinese human genetic data are governed for almost two decades by the Interim Measurements for Human Genetic Resources Administration 1998. The fact that such measures were jointly issued by the Ministry of Science and Technology and Ministry of Health reflects the dual nature of genomic data: they are critical information concerning an individual's health and identity, on the one hand, and invaluable resources for biomedical research and industry, on the other. The dual nature contributes to the compartmentalisation of</i></p>

	<p><i>regulatory approaches and protracted making of a unitary law. With the 2012 Draft Regulations on Human Genetic Resources yet to be enacted, a series of policy initiatives have been undertaken to promote data-driven biomedical research and safeguard national genetic resources. Though these initiatives have improved privacy protection in genomic data sharing, the dual nature of such data remains to be more fully appreciated, and the value of individual autonomy better supported by operable rules.</i></p> <p>Speaker: Dr Clement Chen, Postdoctoral Fellow, Faculty of Law, The University of Hong Kong</p>
4:30pm – 5:00pm	<p>Roundtable Discussion and Q & A</p> <p>Panel Chair: Dr Ron Zimmern, Chairman of the Board of Trustees, PHG Foundation, Cambridge</p>
End of Part II of symposiums	