CMEL

THE UNIVERSITY OF HONG KONG
CENTRE FOR MEDICAL ETHICS AND LAW

The Centre for Medical Ethics and Law (CMEL) develops new ideas and solutions in response to the big ethical, legal and policy questions of medicine and health.

Personal Data Protection Regimes and the Sharing of Human Genetic Data for Research

22 April 2022, Friday

8:00 pm–9:30 pm (Hong Kong Time)
Live Zoom Session

CHAIR:

Introduction and Brief Remarks on Genome Data Sharing in Hong Kong SAR
Dr Calvin Ho
Associate Professor of Law & Co-Director of the Centre for Medical Ethics and Law, The University of Hong Kong

SPEAKERS:

An ethical perspective on the implications of the Personal Information Protection Law for human genomic research in China
Dr Haihong Zhang
Office Director of Peking University Human Research Protection Programme, Health Science Center, Peking University

The impact of the UK and EU General Data Protection Regulation (GDPR) on international genomic data sharing for research
Dr Colin Mitchell
Head of Humanities, PHG Foundation, University of Cambridge

Canadian Genome Data Sharing: Lessons learned from the experience of the CanCOGeN Network
Prof Yann Joly
Research Director of the Centre of Genomics and Policy (CGP)
Professor, Department of Human Genetics, Faculty of Medicine
McGill University

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Co-organised by:

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PHG
FOUNDATION
making science work for health

About the Webinar

Human genomic research and innovation are dependent on access to large quantities of data. The "open science" movement has thus gained momentum and fosters the sharing of personal data, datasets, and research results. In such a context, research participants are encouraged to share their genetic materials to support scientific progress as a common good and researchers are encouraged to share their data on the basis that it can maximise the use of a valuable resource, and also lead to more reproducible science. In this webinar, our speakers consider the impact of personal data protection laws in Hong Kong SAR, Mainland China, Canada, the European Union and the United Kingdom on the sharing of human genetic data for biomedical research, as well as the "open science" movement more generally.

Programme

Personal Data Protection Regimes and the Sharing of Human Genetic Data for Research

Friday, 22 April 2022
8:00 pm – 9:30 pm (Hong Kong Time)

Live Zoom Session

8:00–8:10	**Chair:** **Dr Calvin Ho** Associate Professor of Law & Co-Director of the Centre for Medical Ethics and Law, The University of Hong Kong, Hong Kong, China **Introduction and Brief Remarks on Genome Data Sharing in Hong Kong SAR**
8:10–8:30	**Presentation 1:** **Dr Haihong Zhang** Office Director of Peking University Human Research Protection Programme, Health Science Center, Peking University, China ***Title:*** ***An ethical perspective on the implications of the Personal Information Protection Law for human genomic research in China***

8:30–8:50	**Presentation 2:** **Dr Colin Mitchell** Head of Humanities, PHG Foundation, University of Cambridge, United Kingdom ***Title:*** ***The impact of the UK and EU General Data Protection Regulation (GDPR) on international genomic data sharing for research***
8:50–9:10	**Presentation 3:** **Prof Yann Joly** Research Director, Centre of Genomics and Policy (CGP) Professor, Department of Human Genetics, Faculty of Medicine McGill University, Canada ***Title:*** ***Canadian Genome Data Sharing: Lessons learned from the experience of the CanCOGeN Network***
9:10–9:30	**Discussion**

Abstracts

PRESENTATION 1

Dr Haihong Zhang
Office Director of Peking University Human Research Protection Programme, Health Science Center, Peking University, China

Title:
An ethical perspective on the implications of the Personal Information Protection Law for human genomic research in China

On November 1st, 2021, the Personal Information Protection Law of China came into effective, and introduced legal requirements for processing of personal information. Research that involves the collection, storage, use, analysis, transmission, disclosure and deletion of personal information must comply with these requirements. For instance, the informed consent of the data subject must be obtained. This and other requirements could obstruct socially valuable research, including low risk big data research that involves the retrospective analysis of databases comprising personal information that has not been collected and stored for research purposes. This presentation highlights some of the key challenges that are faced by IRBs and researchers, as well as some measures that could be considered.

PRESENTATION 2

Dr Colin Mitchell
Head of Humanities, PHG Foundation, University of Cambridge, United Kingdom

Title:
The impact of the UK and EU General Data Protection Regulation (GDPR) on international genomic data sharing for research

This presentation will discuss the challenges for international genomic data sharing raised by the European Union's General Data Protection Regulation (GDPR) and the UK's closely aligned version of the same regulation. It will draw on PHG Foundation research on the impact of the GDPR on genomic healthcare and research and provide an updated assessment of how the specific rules in Chapter V of the Regulation apply to international transfers of genomic data. We will also consider potential solutions and mechanisms to facilitate the sharing of genomic data between the EU/EEA and the rest of the world.

PRESENTATION 3

Prof Yann Joly
Research Director, Centre of Genomics and Policy (CGP)
Professor, Department of Human Genetics, Faculty of Medicine
McGill University, Canada

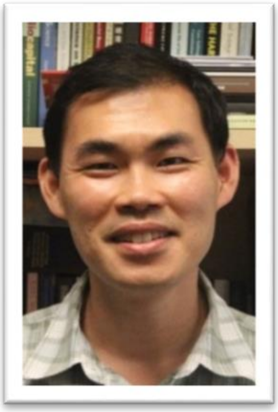
Title:
Canadian Genome Data Sharing: Lessons learned from the experience of the CanCOGeN Network

The proposed communication will address current challenges in sharing genomic data, within Canada and, between Canada and other countries. It will use a case study approach to illustrate the various hurdles to data sharing based on the author's experience of the past two years as Chair of the CanCOGeN data sharing Committee. CanCOGeN coordinated a pan-Canadian, cross-agency network for large-scale SARS-CoV-2 and human host genome sequencing and sharing. In addition to reviewing the CanCOGeN data sharing activities, we will present the main recommendations of the 'lessons learned' issue paper developed by CanCOGeN's data sharing committee.

Biographies

CHAIR

Dr Calvin Ho
Associate Professor of Law & Co-Director of the Centre for Medical Ethics and Law, The University of Hong Kong



Dr Calvin Ho is Associate Professor with the Faculty of Law, and Co-Director of the Centre for Medical Ethics, at the University of Hong Kong. His research is primarily on the governance of health and biomedical technologies, including human genome editing, human pluripotent stem cell research, and health technologies based on Artificial Intelligence and data analytics. He is an Ethics Board member of Médecins Sans Frontières (Doctors Without Borders), and a member of the COVID-19 Ethics & Governance Working Group of the World Health Organization.

Biographies

SPEAKERS

Dr Haihong Zhang
Office Director of Peking University Human Research Protection Programme, Health Science Center, Peking University, China

Dr Haihong Zhang received her PhD in research ethics from Peking University (PKU) and is now working at PKU Human Research Protection Program. In the past ten years, she and her team developed institutional ethics review working procedures and policies at PKU. She is in-charge of the PKU investigators' research ethics training program and teaches medical students clinical research ethics. Her research interests are protection of vulnerable research subject, IRB capacity building and data ethics.

Dr Colin Mitchell
Head of Humanities, PHG Foundation, University of Cambridge, United Kingdom

Dr Colin Mitchell is Head of Humanities at the UK based health policy think tank, the PHG Foundation, which is part of the University of Cambridge. He leads a team addressing legal and ethical issues that arise with genomics and other biomedical innovations. This includes challenges associated with genomic data processing, artificial intelligence and the obligations of health and scientific professionals in the contemporary biomedical landscape. Colin has a PhD in health law from the University of Amsterdam, a Masters of Studies in Legal Research from the University of Oxford and a BA in Law from the University of Cambridge.

Prof Yann Joly
Research Director, Centre of Genomics and Policy (CGP)
Professor, Department of Human Genetics, Faculty of Medicine
McGill University, Canada

Yann Joly, Ph.D. (DCL), FCAHS, Ad.E. is the Research Director of the Centre of Genomics and Policy (CGP). He is a Full Professor at the Department of Human Genetics at McGill University. He was named advocatus emeritus by the Quebec Bar in 2012 and Fellow of the Canadian Academy of Health Sciences in 2017. In 2021 he received, the Canadian Science Policy Centre, Science Policy Trailblazer Award. Prof. Joly's research interests lie at the interface of the fields of scientific knowledge, health law (biotechnology and other emerging health technologies) and bioethics. He created the first international genetic discrimination observatory in 2018.

About CMEL

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The Centre for Medical Ethics and Law (CMEL) develops new ideas and solutions in response to the big ethical, legal and policy questions of medicine and health. CMEL is the first cross-faculty interdisciplinary institution of its kind in the region. It was founded in 2012 by the LKS Faculty of Medicine and Faculty of Law at The University of Hong Kong as a joint inheritor of their vibrant intellectual traditions dating back to 1887 and 1969 respectively.

Today, CMEL brings together bioethicists, academic lawyers, medical scientists, and other scholars to conduct cutting edge bioethical and legal research and contribute to policy development in flagship areas like digital health and emergent technologies, mental health and capacity, and population and global health.

Research, teaching and knowledge exchange—CMEL's core initiatives—aim to ensure that developments in biomedicine and public health will be underpinned by ethical and legal considerations.

Centre for Medical Ethics & Law, The University of Hong Kong

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