



CMEL
THE UNIVERSITY OF HONG KONG
CENTRE FOR MEDICAL ETHICS AND LAW



Regulatory Governance of **Genomics &** Reproductive Technologies

4-6 December 2023
Hong Kong & ZOOM

11/F, Cheng Yu Tung Tower, Centennial Campus, HKU
& via ZOOM

With support from the Medical Ethics & Humanities Unit (Faculty of Medicine), the Centre for Medical Ethics and Law is delighted to present an international conference that seeks to examine the nature and implications of the regulatory governance of emerging health technologies, with focus on recent developments in reproductive health and genomic medicine. In this connection, we consider the rise of the regulatory state in promoting biomedical research and development (R&D) through the use of direct and indirect rules, and in the variety of regulatory regimes involving non-state actors (e.g., private regulation, self-regulation and civil regulation) that have emerged. Key questions to be addressed at this conference include:

1. What is the “regulatory state” vis-à-vis biomedical R&D, who are the key actors and what are their roles?
2. What is law in the “regulatory state” and what is its contribution to this phenomenon and to biomedical R&D?
3. What is bioethical in the “regulatory state” and what is its contribution to this phenomenon and to biomedical R&D?
4. To what extent are the goals of (2) consistent with those of (3)? How are conflicts (if any) resolved?
5. What are the normative implications of the rise of the “regulatory state” on global governance of biomedical R&D?

Recent advances in genetics and human reproductive technologies continue to present distinctive ethical and legal challenges. For instance, advances in high-throughput sequencing technologies have enabled the detection of chromosomal abnormalities in a foetus through non-invasive prenatal testing (or NIPT). Expanded testing conducted in NIPT has further raised concerns as to whether a child’s right to an open future requires parental freedoms to be curtailed. In a research context, it is as yet unclear whether and when actionable genomic results in a research biobank should be returned to an individual or otherwise shared with third parties who could potentially benefit from having access to these results. In this international conference, leading scholars examine the nature and implications of the regulatory governance of emerging genetic and reproductive technologies, as well as the rise of the regulatory state in promoting biomedical research and development (R&D) through the use of direct and indirect rules, and in the variety of regulatory regimes involving non-state actors (e.g., private regulation, self-regulation and civil regulation) that have emerged.

Simultaneous Interpretation in English and Mandarin will be available.

Monday 4 December 2023

Afternoon 14:15–18:15: Advances in Genomics
Evening 19:00–20:30 WNG–Hatton Lecture 2023

Tuesday 5 December 2023

10:00–18:15: Reproductive Technologies

Wednesday 6 December 2023

Morning 9:15–13:00: Access to Emerging Technologies

Monday 4 December 2023 – Afternoon

Advances in Genomics

14:15-14:30 **Welcome and Introductory Presentations**

Gilberto K.K. Leung ◦ 梁嘉傑

Li Ka Shing Faculty of Medicine & Centre for Medical Ethics and Law, The University of Hong Kong

Calvin W.L. Ho ◦ 何維倫

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

14:30-15:00 **Rethinking Governance: Developing a Technology-Agnostic Ethical Governance Framework for Emerging Technology**

Katherine Littler

Health Ethics & Governance Unit, World Health Organization, Geneva

15:00-15:30 **Interpreting the New Ethical Standards in China for Cutting-Edge Science and Technology**

Xiaomei Zhai ◦ 翟晓梅

Chinese Academy of Medical Sciences & Peking Union Medical College, Beijing

15:30-16:00 **The Regulatory Role of ‘Sufficiency of Disclosure’ in Patent Law for Emerging Medical Technologies**

Kathleen Liddell & Mateo Aboy

Centre for Law, Medicine and Life Sciences, University of Cambridge

16:00-16:15 **Intermission**

16:15-16:45 **How International Comparative Law Can Become a Driver for Legal Reform at the National Level: The Example of the International Genetic Discrimination Observatory**

Yann Joly

Centre for Genomics and Policy, McGill University, Montréal

16:45-17:15 **Are Synthetic Health Data ‘Personal Data’? Whether, or in What Circumstances, Synthetic Health Data might be Considered ‘Personal Data’ under the UK and EU GDPR**

Colin Mitchell

PHG Foundation, University of Cambridge

17:15-17:45 **Participatory Governance in Genomics Research: Return of Results and Group Consent**

Chih-Hsing Ho ◦ 何之行

Institute of European and American Studies, Academia Sinica, Taipei

17:45-18:15 **Indigenous Research Ethics Governance in Japan and Its Implications for Genomics**

Momoko Sato ◦ 佐藤桃子

Laboratory for Biomedical Ethics and Co-Design, RIKEN, Tokyo

Monday 4 December 2023 – Evening WYNG-Hatton Lecture 2023

19:00-20:30

Smart Regulation for Medical Innovation

Sir Jonathan Montgomery

Faculty of Laws, University College London

Commentators:

Wei Zhu · 朱伟

Applied Ethics Center and Department of Social Sciences, Fudan University

Ping Ji · 吉萍

Clinical Research Institute, Shenzhen-PKU-HKUST-Medical Center, Shenzhen

20:30-21:30 Dinner

(for registered attendees of the WYNG-Hatton Lecture)

Tuesday 5 December 2023

Reproductive Technologies

10:00-10:15 **Introductory Remarks**

Gilberto K.K. Leung ◦ 梁嘉傑

Li Ka Shing Faculty of Medicine & Centre for Medical Ethics and Law, The University of Hong Kong

Calvin W.L. Ho ◦ 何維倫

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

10:15-10:45 **Exploring Different Approaches to Governance**

Jane Kaye

Centre for Law, Health and Emerging Technologies (HeLEX), University of Oxford

10:45-11:15 **Ethical Framework/Approach for the Hong Kong Genome Project**

Derrick Au ◦ 区结成

Honorary advisor, Centre for Bioethics, the Chinese University of Hong Kong /
Convenor of EAC, Hong Kong Genome Institute

11:15-11:30 **Intermission**

11:30-12:00 **Governance of Embryo-like structures**

Sarah Chan

The Usher Institute, University of Edinburgh

12:00-12:30 **Embryo Research, 'The 14 Day Rule', and the Political Morality of Legislation**

Sir Jonathan Montgomery

Faculty of Laws, University College London

12:30-14:00 **Lunch**

14:00-14:30 **Regulating Technologies of Reproduction**

Catherine Mills

School of Philosophical, Historical and International Studies, Monash University,
Melbourne

14:30-15:00 **Mitochondrial Donation – The Australian Story**

Bernadette Richards

Academy of Medical Education, University of Queensland, Brisbane

15:00-15:30 **Personalist (Dignitarian) Approach to the Governance of Reprogen Medicine**

Joseph Tham ◦ 譚傑志

School of Bioethics, Regina Apostolorum Pontifical University, Rome

15:30-15:45 **Intermission**

- 15:45-16:15 **Implementing New Genomic Sequencing Technologies at the Start of Life: The Importance of Bioethics to Regulatory Processes**
Ainsley Newson
Sydney Health Ethics, Sydney School of Public Health
- 16:15-16:45 **Confucian reflection on the new Reproductive Model of ROPA**
Yonghui Ma • 马永慧
Center for Bioethics, School of Medicine, Xiamen University
- 16:45-17:00 **Intermission**
- 17:00-17:30 **The Impossibility and Inevitability of Innovation in Human Reproductive Biology: Norms and Limits**
Peter Mills
PHG Foundation, University of Cambridge
- 17:30-18:00 **The Future of Human Reproduction**
Sara J. Fovargue
Sheffield Law School
- 18:00-18:15 **Closing Remarks**

Wednesday 6 December – Morning

Access to Novel Technologies

09:15-09:30 **Introductory Remarks**

Gilberto K.K. Leung ◦ 梁嘉傑

Li Ka Shing Faculty of Medicine, & Co-Director, Centre for Medical Ethics and Law,
The University of Hong Kong

Calvin W.L. Ho ◦ 何維倫

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

9:30-10:00 **Patient Involvement in Research and Access to Benefits**

Kaori Muto ◦ 武藤香织

Institute of Medical Sciences, University of Tokyo

10:00-10:30 **The Evolving Landscape of Novel Technologies in Australia: We know where we're going, but how will we get there?**

Matilda Haas

Australian Genomics, Melbourne

10:30-11:00 **Governance of Reproductive Technologies in Hong Kong**

Olivia Ngan ◦ 顏妙融

Medical Ethics & Humanities Unit, Li Ka Shing School of Medicine, The University of
Hong Kong

11:00-11:15 **Intermission**

11:15-11:45 **Ethical Issues facing Insurers in the Changing Landscape**

Caitlyn A. Tabor

Center for Law, Brain & Behavior, Harvard Medical School, Cambridge, MA

11:45-12:15 **Ethical and Legal Challenges facing the Translation of Polygenic Scores into Healthcare**

Tanya Brigden

PHG Foundation, University of Cambridge

12:15-12:45 **Challenges to Equitable Sharing of Benefits in mHealth Research**

Barry Solaiman

College of Law, Hamad Bin Khalifa University, Doha

12:45-13:00 **Closing Remarks**

13:00-14:30 **Lunch**

About the Organisers

Organised by:



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. 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 and Law, The University of Hong Kong

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