



2018 第四屆「專業倫理」教學國際論壇
International Forum on Teaching Professional Ethics

大會主題：專業倫理跨域教育的養成	
2018.12.12(三)「專業倫理」教學論壇議程	
09:20-09:50	報到(地點：中原大學張靜愚紀念圖書館一樓秀德廳)
09:50-10:00	■ 主席致詞
10:00-12:00	<p>大會專題演講：大數據時代的遺傳歧視 Genetic Discrimination in the Big Data Era (專題演講 90mins、交流 30mins)</p> <p>■ 主講人：Dr. Calvin Wai-Loon Ho (新加坡大學生物醫學倫理中心)</p> <p>■ 主持人：中原大學 陳怡寧(產業加速器暨育成中心主任) Yi-Ning Chen, Director of Innovation and Incubation Center</p> <p>■ 與談人：</p> <ol style="list-style-type: none"> 1. 臺北醫學大學 李崇僊(醫療暨生物科技法律研究所所長) Chung-Hsi Lee, Associate Professor and Chairman of Graduate Institute Of Health And Biotechnology Law 2. 中原大學 吳宗遠(副研發長) Tzong-Yuan Wu, Vice Dean of Office of Research and Development 3. 中原大學 陳中庸(生科系主任) Chung-Yung Chen , Chairman of Department Of Bioscience Technology
2018.12.12(三)全國專業倫理教師座談	
13:10-13:25	報到(地點：中原大學 活動中心 2F 多功能展演廳)
13:25-13:30	主席致詞：夏誠華教務長 Chen-Hwa Hsia, Dean of The Office Of Academic Affairs
13:30-14:20	<p>主題：專業倫理多領域教育的養成(I):專業倫理課程設計 (演講 20 mins、交流 25mins)</p> <p>■ 主講人：Dr. Calvin Wai-Loon Ho</p> <p>■ 與談人：</p> <ol style="list-style-type: none"> 1. 中原大學 饒 忻(學務長) Hsin Rau, Dean of The Office Of Student Affairs 2. 中原大學 吳宗遠(副研發長) Tzong-Yuan Wu, Vice Dean of Office of Research and Development 3. 中原大學 高欣欣(校牧室主任) Shin-Shin Kao, Professor and Chairman of Chaplain`S Office
14:20-14:30	中場休息
14:30-15:15	<p>■ 主題：專業倫理多領域教育的養成(II):學術倫理在研究的實踐與困難 (演講 30mins、交流 15mins)</p> <p>■ 主講人：Dr. Calvin Wai-Loon Ho</p> <p>■ 引言人：</p> <ol style="list-style-type: none"> 1. 中原大學 謝明發(工學院副院長) Ming-Fa Hsieh, Vice Dean of College of Engineering 2. 中原大學 嚴奇峰(商學院院長) Ghi-Feng Yen , Dean of College Of Business

2018.12.13(四)專題研討

9:40-9:55	報到(地點：中原大學 維澈大樓 9F 領導力中心)
10:00-12:00 (中場休息 10 分鐘)	主題： 生物醫學研究中生物材料及相關數據的獲取和利益分享的社會價值 Social Value in Access to and Benefit Sharing of Biological Materials and related Data in Biomedical Research(演講 90mins、交流 20mins) ■ 主講人：Dr. Calvin Wai-Loon Ho ■ 主持人：中原大學 陳怡寧(產業加速器暨育成中心主任) Yi-Ning Chen, Director of Innovation and Incubation Center

Calvin Wai-Loon Ho Biography

講員簡介網址：<http://cbme.nus.edu.sg/people/all-staff/dr-calvin-ho>

中文簡介：

新加坡大學生物醫學倫理中心，

新加坡世界衛生組織生物倫理合作中心聯合負責人、全球基因組與健康聯盟問責政策任務組聯合負責人。擁有康奈爾大學（紐約）的法律科學博士學位，並在新加坡國立大學和劍橋大學（英格蘭）接受法律培訓。擁有倫敦政治經濟學院社會學和經濟學學位，以及倫敦大學東方和非洲研究學院的學位。

- Journal Asian Bioethics Review 期刊主編、無國界醫生組織倫理委員會成員、新加坡法律援助局助理主任、新加坡護理委員會和衛生部移植和基因檢測諮詢委員會成員。
- 發表生物醫學法律和倫理、健康政策和系統以及全球健康等文章，也是新加坡生命倫理學的共同編輯：道德微觀世界（2010）、遺傳隱私（2013）；生物倫理法學：人類多能細胞研究治理（2016）、世界衛生組織公共衛生監督倫理問題指南（2017）。

英文簡介：

Calvin W. L. Ho NUS Centre for Biomedical Ethics, Co-Head of the WHO Collaborating Centre for Bioethics in Singapore, and Co-Head of the Accountability Policy Task Team of the Global Alliance for Genomics & Health. He holds a doctorate in juridical science from Cornell University (New York), and was also trained in law at NUS and University of Cambridge (England). In addition, he holds degrees in sociology and economics at the London School of Economics and Political Science, and at the School of Oriental and African Studies (University of London).

He is also the Editor-in-Chief of the journal Asian Bioethics Review (published by Springer Nature), and an Ethics Board member of Médecins Sans Frontières (Doctors Without Borders). Additionally, he serves as an Assistant Director with the Legal Aid Bureau of the Ministry of Law (Singapore), as well as on the Singapore Nursing Board and advisory committees for transplantation and for genetic testing of the Ministry of Health (Singapore). He has published on biomedical law and ethics, health policy and systems, and global health, and is the co-editor of Bioethics in Singapore: An Ethical Microcosm (2010, World Scientific) and Genetic Privacy (2013, Imperial College Press), the author of Juridification in Bioethics: Governance of Human Pluripotent Cell Research (2016, Imperial College Press), as well as an author of the WHO Guidelines on Ethical Issues in Public Health Surveillance (2017).

Abstract :



Genetic Discrimination in the Big Data Era

大數據時代的遺傳歧視

Calvin W. L. Ho

Establishment of human genetic databases has led to discussions on whether a general ethical or legal framework can adequately address concerns over discrimination and privacy (in its informational and decisional aspects) in the Big Data Era. A question in this debate is whether a more specialised framework should be conceptualised to provide more appropriate guidance, especially when different ethical principles or regulatory goals come into conflict. A related consideration is whether this more specialized framework will provide different responses to informed consent and data sharing. With reference to the European Union's General Data Protection Regulation that entered into force in 2018, this paper evaluates what genetic discrimination could mean in relation to the conceptualisation and practice of privacy, as well as on data sharing. Genetic discrimination is a complex notion because it encapsulates overlapping interests and concerns that arise from our needs as human beings, commonly manifested in different types and levels of dependencies. Importantly, it can be a useful analytic in ethical deliberation and action, through the explication of whether and how healthcare and research interventions should follow for a given population and who should have what responsibilities, as well as the ethical goals that should be prioritised. This paper further argues that a combination of ethical and/or regulatory approaches is required in order to sustain a moral space by which situational expectations and practices could be negotiated and implemented at different levels.

人類基因資料庫在大數據時代來臨下開始建立，但在使用或依據人類基因資料進行決策所產生的隱私及歧視問題時，一般道德及法律系統是否能解決或保護個人的權利。尤其是當不同道德倫理原則與管理目標發生衝突時，主要論述在於是否需要建立並概念化更專一特別的法律框架來做適當的規範。而“受試者知情同意”和“資訊共享”可能對這特別的法律框架有不同的要求。據歐盟於 2018 年生效的“一般數據保護條例”，本文評估了遺傳歧視的概念化對隱私權保護及資訊共享的意義。遺傳歧視是一個複雜的概念，因為它包含了我們作為人類需求產生的重疊利益和關注，通常表現在不同類型和級別的依賴關係中。重要的是，通過闡明醫療保健和研究干預措施是否以及如何應對特定人群以及誰應該承擔哪些責任以及應優先考慮的道德目標，它可以成為道德審議和行動的有用分析。本文進一步討論是否需要結合道德和/或監管方法，以維持能在不同層面上協商和實施情境期望和實踐的道德空間。

Abstract :



Social Value in Access to and Benefit Sharing of Biological Materials and related Data in Biomedical Research

生物醫學研究中生物材料及相關數據的獲取和利益分享的社會價值

Calvin W. L. Ho

This paper argues that social value must remain a central consideration for issues on accessing, and benefit sharing of, biological materials and related data in biomedical research (ABS). The argument is made in two contexts (local and global) but its central concern relates to the type of control that interested individuals and institutions should have, as well as why social value could matter more. In a local context, the paper will discuss recent legislative and regulatory changes on the topic in Singapore, where considerable emphasis has been placed on informed consent. While such a focus may be consistent with legal principles and is operationally important, it may ultimately constrain the right to science (in international law conventions) unless the principle of social value is given equal or perhaps even greater emphasis. In a global context, the paper will evaluate ABS within the normative framework established by the Convention on Biological Diversity and supplemented by the Nagoya Protocol, particularly in relation to the sharing of human pathogens. In considering the challenges that arose in relation to the sharing of the H5N1 pathogen during the outbreak in 2007, this paper seeks to explain – in both the local and global contexts – how the principle of social value could be conceptualized and applied for the purposes of ABS, and why it should matter more.

本文章提出在針對生物醫學研究 (ABS) 中生物材料和相關數據的獲取以及利益分享的議題上，社會價值必須維持為核心考量。論述從地區性和全球性的議題上來討論有利害關係的個人及機構應當擁有的控制權，以及為何社會價值應凌越這些控制權。在地區性的議題上，以新加坡最近對“受試者知情同意”所做的立法及管理變化來討論。雖然專注在“知情同意”的權利符合法律原則及實行上的重要性，但這種作法可能會限制在國際法公約中的科學研究權利，除非社會價值原則得到平等或甚至更大的重視。在全球性議題上，針對“生物多樣性公約”及“名古屋議定書”中生物材料及資料共享原則進行討論，尤其是分享人類病原體方面。以 2007 年爆發禽流感 H5N1 後對分享 H5N1 病原的挑戰性為例，本文希望從地區性及全球的角度來了解社會價值原理概念化並應用於生物醫學研究 (ABS) 上的重要性。