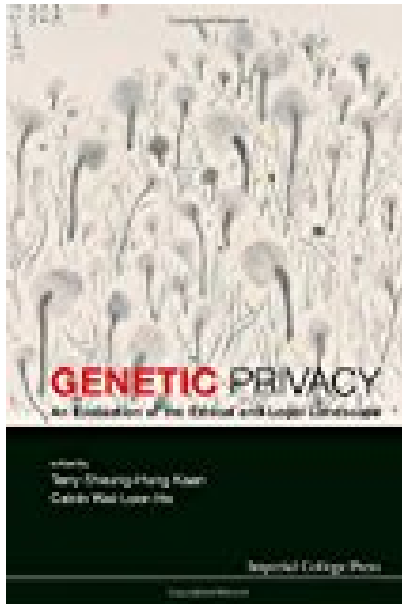


# Genetic Privacy An Evaluation of the Ethical and Legal Landscape

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## BOOK DETAILS

- Author : Terry Sheung-Hung Kaan
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## BOOK SYNOPSIS

Privacy is an unwieldy concept that has eluded an essentialised definition despite its centrality and importance in the body of bioethics. The compilation presented in this volume represents continuing discussions on the theme of privacy in the context of genetic information. It is intended to present a wide range of expert opinion in which the notion of privacy is examined from many perspectives, in different contexts and imperatives, and in different societies, with the hope of advancing an understanding of privacy through the examination and critique of some of its evolving component concepts such as notions of what constitute the personal, the context of privacy, the significance and impact of the relational interests of others who may share the same genetic inheritance, and mechanisms for the protection of privacy (as well as of their limitations), among others. More specifically, the discussions in this volume encourages us to think broadly about privacy, as encompassing values that are entailed in the sociality of context and of relations, and also as freedom from illegitimate and excessive surveillance. A long-standing question that continues to challenge us is whether genetic information should be regarded as exceptional, as it is often perceived. A conclusion that could be derived from this volume is that while genetic information may be significant, it is not exceptionally so. The work presented in this volume underlines the continuing and growing relevance of notions of privacy to genomic science, and the need to take ownership of a genetic privacy for the future through broad, rigorous and open discussion. Contributors: Alastair V Campbell, Benjamin Capps, Jacqueline JL Chin, Oi Lian Kon, Kenji Matsui, Thomas H Murray, Nazirudin Mohd Nasir, Dianne Nicol, Anh Tuan Nuyen, Onora O'Neill, Margaret Otlowski, Yvette van der Eijk, Chunshui Wang, Ross S White. Contents: The Notion of Genetic Privacy (Calvin WL Ho and Terry SH Kaan) Can Data Protection Secure Personal Privacy? (Onora O'Neill) Navigating the Privacy Complex of Self, Other and Relationality (Calvin WL Ho) Privacy and Biomedical Research: A Role-based Approach (Anh Tuan Nuyen) Socio-political Discourses on Genetic Privacy in Japan (Kenji Matsui) Genetic Privacy: A Challenge to Genetic Testing in China (Chunshui Wang) Don't Ask, Don't Tell: Exploring the Limits of Genetic Privacy in Singapore (Terry SH Kaan) Privacy, Rights and Biomedical Data Collections (Benjamin Capps) Individual Right vs. Public Interest: The Role of the Islamic Religious Council of Singapore in Bioethics Consultation on Genetic Privacy (Nazirudin M Nasir) What — If Anything — Is Special about "Genetic Privacy"? (Jacqueline JL Chin and Alastair V Campbell) Genetic Privacy in the United States: Genetic Exceptionalism, GINA, and the Future of Genetic Testing (Thomas H Murray and Ross S White) The Regulatory Framework for Protection of Genetic Privacy in Australia (Margaret Otlowski and Diane Nicol) Privacy Matters in Nicotine Addiction (Yvette van der Eijk) Human Genomics and Privacy (Oi Lian Kon) Readership: Students and professionals in medical law and medical ethics, public policy, Asian studies and public health. Keywords: Bioethics; Biotechnology; Genetics; Policy; Public; Trust; Regulation of Research; Singapore; Privacy

**GENETIC PRIVACY AN EVALUATION OF THE ETHICAL AND LEGAL**

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