



CUHK Centre for Bioethics Webinar Series

“Seminar on Genomics - Ethical and Governance Considerations for Reproductive Genetic Screening”

23 November 2021 (Tue)
10:00 a.m. – 11:45 a.m. (Hong Kong Time) /
1:00 p.m. – 2:45 p.m. (Sydney/Melbourne Time) /
3:00 p.m. – 4:45 p.m. (New Zealand Time)

Online via Zoom

Abstracts & Biographies of Speakers/Discussants

Prof. Ainsley NEWSON

“Ethical Issues in Large-Scale Reproductive Genetic Carrier Screening Programs: A View from Australia”

Genetic carrier screening to inform reproductive decisions has existed for over half a century. Originally offered to those from certain ethnic groups, or (as carrier testing) to those with a family history of a particular genetic condition, it is now being scaled up for much wider population implementation. This change has been enabled by both technological advancements in DNA sequencing methods and increased knowledge of how genetic variants influence human health. Australia is one of a few countries globally that are utilising these advances to trial a large-scale population offer of reproductive genetic carrier screening (RCS). The Australian Reproductive Carrier Screening Project (‘Mackenzie’s Mission’) pilot project is currently underway and will offer RCS to up to 8,500 Australian couples. The project aims to provide evidence across several domains – including bioethics – to inform a future government-funded RCS screening offer. In this presentation, I will discuss a range of ethical issues that arise in initiatives like Mackenzie’s Mission, including considerations relating to the selection of genes to screen for, the relevance of public health ethics to program design and implementation, and ensuring RCS programs reflect wider community values.

Ainsley Newson is Professor of Bioethics at Sydney Health Ethics, University of Sydney. Her research focuses on ethical aspects of genomics and human reproduction, with the aim to ensure these technologies are developed and used appropriately and fairly. Ainsley’s current research projects are examining new genomic technologies in prenatal testing, reproductive carrier screening, the implementation of genomics in publicly funded health care systems, commercial influences in assisted reproduction and mitochondrial donation. Her research has generated over 150 academic, policy and general interest publications.



Dr. Calvin Wai Loon HO

“Responsible Implementation of Expanded Prenatal Genetic Testing in Hong Kong and Singapore: Whose Job Is It?”

In Hong Kong, universal screening for Down syndrome has been freely available since July 2010, while non-invasive prenatal testing (NIPT) has been available as a self-paid service since August 2011. Similar to the United Kingdom, NIPT for aneuploidy is only offered to women considered to be at high risk. In other jurisdictions like the United States of America, some scholars have observed a trend towards offering foetal genetic screening to women regardless of risk. The capability of using NIPT to test for an increasingly broad range of diseases in a foetus has raised the question of whether access to the test should be restricted. This presentation argues, in the contexts of Hong Kong and Singapore, that while there is no compelling ethical or legal reason to restrict access to expanded NIPT (which may involve whole exome and whole genome sequencing), oversight by medical professional bodies and regulators is required if it is applied.

Calvin Wai-Loon 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 Access to COVID-19 Tools (ACT) Accelerator Ethics Working Group of the World Health Organization.

Prof. Catherine MILLS

Catherine Mills is Director of the Monash Bioethics Centre at Monash University, where she previously held an ARC Future Fellowship. Her research addresses ethical issues that arise around innovative reproductive biomedicine and technologies. In current funded research projects, she examines genomics for preventing mitochondrial disease, expanded non-invasive prenatal testing, epigenetics in antenatal care, uterine transplant and commercial interests in IVF. She has an extensive record of academic publication, including three sole author books - *The Philosophy of Agamben* (2008), *Futures of Reproduction: Bioethics and Biopolitics* (2011) and *Biopolitics* (2018).



Ms. Josephine JOHNSTON

Josephine Johnston is Director of Research and a Research Scholar at The Hastings Center, an independent bioethics research institute in Garrison, New York, and Lecturer at the University of Otago's Bioethics Centre in Dunedin, New Zealand. She works on the ethics of emerging biotechnologies, particularly as used in human reproduction, psychiatry, genetics, and neuroscience. Her scholarly work has appeared in medical, scientific, policy, law, and bioethics journals, including *New England Journal of Medicine*, *Science*, *Nature*, *Hastings Center Report*, and *Journal of Law, Medicine and Ethics*. She is co-editor of *Human Flourishing in an Age of Gene Editing* (Oxford University Press, 2019) and *Trust and Integrity in Biomedical Research: The Case of Financial Conflicts of Interest* (Johns Hopkins University Press, 2010). Ms. Johnston holds degrees in law and bioethics from the University of Otago in New Zealand.