



CUHK Centre for Bioethics Webinar Series

Seminar on “Genomics for Health – Addressing Ethical and Social Concerns”

11 May 2021 (Tue)

10:30 a.m. – 12:15 p.m. (Hong Kong Time) /

12:30 p.m. – 2:15 p.m. (Sydney/Melbourne Time) /

2:30 p.m. – 4:15 p.m. (New Zealand Time)

Online via Zoom

Abstracts & Biographies of Speakers/Discussants

Prof. Catherine MILLS

“Your Choice: Reproductive Autonomy in Prenatal Testing”

Abstract & Bio: Pending

Ms. Josephine JOHNSTON

“Sequencing Newborns: A Case for Nuanced Use of Genomic Technologies”

Abstract: In November 2019, the U.K.’s Minister of Health announced a plan to sequence the genome of every baby born in a National Health Service hospital, beginning with a pilot of 20,000 children. The Minister called his plan a “genomic revolution,” promising that “whole genome sequencing and genomics would play a huge part” in ensuring that every child receives “predictive, preventive, personalized health care.” Similar enthusiasm has been expressed in the U.S., where the head of the National Institutes of Health, Francis Collins, has said that he looks forward to the day when all babies are sequenced at birth. Such sweeping plans for collecting and sequencing the DNA of newborns may appear bold and tech-forward, but they lack nuance. Sequencing results are voluminous and variable. Some can be used to improve medical care, but others are poorly understood or uncertain, making widespread and untargeted use of the technology a poor use of precious public health dollars. Genome sequencing belongs in newborn health care, but it must be used in targeted ways that are scientifically justified, equitable, and attentive to the needs of babies, families, and health systems.

Josephine Johnston is Director of Research and a Research Scholar at The Hastings Center, an independent bioethics research institute in Garrison, New York. 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.



Prof. Ainsley NEWSON

Ainsley Newson is Professor of Bioethics at Sydney Health Ethics, University of Sydney. Ainsley holds degrees in bioethics, law and science, and has worked continuously in bioethics for over 20 years. Her research uses normative and empirical methods to assess how genomic and reproductive technologies should be used well, in both clinical and population health settings. Ainsley addresses key practical challenges in genomic and reproductive medicine and in doing this she has forged successful collaborations with clinical and research geneticists as well as with other bioethics and law academics. She has published over 120 peer-reviewed papers and book chapters and has been a chief investigator in research grants that have attracted over AUD\$65m in funding. In addition to her academic research, Ainsley is an active contributor to policy regarding genomics and reproduction in Australia, and is a regular media commentator regarding bioethics issues.

Dr. Calvin Wai-Loon HO

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.

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