

Inaugural Asian Paediatric Ethics Conference 2nd and 3rd October 2023



Plenary 1 speaker

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Brian trained at HKU (2000-2006) and University of Toronto (the Hospital for Sick Children, 2007-2010), specializing in Paediatrics and Clinical Genetics. He is a fellow of the Canadian College of Medical Geneticists and was a founding fellow of the subspecialty of Genetics & Genomics (Paediatrics) of the Hong Kong Academy of Medicine (HKAM). His research focuses on (1) the clinical application of whole genome technologies, (2) clinical genetics & genetic counselling and (3) precision medicine and multiomics. He received the Best Young Investigator Prize of the Hong Kong College of Paediatricians in 2017.

Since 2021, Brian has been designated as the Chief Scientific Officer at the Hong Kong Genome Institute and oversees research developments for the Hong Kong Genome Project.

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Abstract

Over the past decade, the rapid advancement in next-generation sequencing and bioinformatic technologies has offered immense potential for integrating genomic medicine into routine paediatric care. However, this presents unique ethical challenges, as it involves making decisions on behalf of children and the potential to obtain unsolicited findings.

One of the key ethical issues in paediatric genomic medicine is the question of when and for which indications genome-wide sequencing should be used. This involves the expertise and training of non-genetics specialists involved in decision-making. Another important aspect is the process of informed consent and pretest counselling, which has become increasingly complex due to the multitude of possible outcomes and complexities of genomic data. Effective communication and genetic counselling are crucial for enabling patients and parents to make well-informed decisions, and providing the necessary resources in terms of finance, personnel, and time is of great importance.

Moreover, the ethical principles associated with genomic research and clinical practice have evolved over the years. Initially, the focus was on individual-focused concepts such as autonomy, privacy, justice, equity, and equality. Later, more communal-focused principles emerged, including reciprocity, mutuality, solidarity, citizenry, and universality. Recently, principles such as governance, security, empowerment, transparency, the right not to know, and globalisation have gained prominence, highlighting the importance of the system within which genomic research and clinical practice operates.

The Hong Kong Genome Project (HKGP), the first large-scale whole genome sequencing (WGS) initiative in the region wholly owned by the Hong Kong government can serve as an example for addressing these ethical challenges in paediatric genomic medicine. The HKGP aims to conduct WGS for 40,000 – 50,000 genomes in five years and focuses on the key areas of: undiagnosed diseases, hereditary cancers and cases related to genomics and precision health. The project complies with data protection principles, develops guidelines and standardised protocols, and ensures participant autonomy with its unique three-tier consent and assent model. This model aims to balance paternalistic and liberal approaches in the international arena while maximising the autonomy and best interests of adolescents.

In conclusion, the ethical considerations in paediatric genomic medicine are complex and multifaceted, involving issues related to the use of genome-wide sequencing, pretest counselling, data analysis and interpretation, communication of results, and future data usage. Ensuring that healthcare professionals, particularly paediatricians, are equipped to navigate these ethical challenges is essential for providing ethically appropriate medical care for children in Asia.