

Panel 6-4. Genetic ELSI and Public Health

Date & Time: Oct. 24 (Thu), 14:00-16:00

Venue: Room 105

Host: Asian Institute for Bioethics and Health Law (AIBHL), Yonsei University

“Genetic ELSI and Public Health”

Moderator	Il Hak Lee	(Professor, College of Medicine, Yonsei University, Korea)
Chair	Il Hak Lee	(Professor, College of Medicine, Yonsei University, Korea)
Panel 6-4. a	Yann Joly	(Professor, McGill University, Canada)
Panel 6-4. b	Su Min Kim	(Researcher, Asian Institute for Bioethics and Health Law, Korea) <i>Legal, and Social Aspects of the ROK's National Project of Bio Big Data</i>
Panel 6-4. c	Junhewk Kim	(Professor, College of Dentistry, Yonsei University, Korea)

Abstract

The rapid rise of genomic technologies and the accessibility of whole genome sequencing (WGS) has led to the commodification of genetic data, raising significant ethical, legal, and social concerns. This presentation argues that the sale of genetic data should be critically restricted due to several reasons.

Firstly, individuals often cannot accurately assess the value of their genetic data at the point of sale, as its true worth may only emerge after research, making initial transactions potentially exploitative. Secondly, selling genetic data typically results in the loss of ownership and control, which could lead to privacy breaches or unforeseen health consequences.

Genetic information is uniquely tied to a person's identity, embodying personal and familial histories, which makes it different from other data. Treating such personal data as a commodity risks undermining human dignity and bodily integrity.

The presentation explores the societal pressures toward data commodification and proposes a framework that respects individual rights while considering technological advancements. It advocates for restrictions on the sale of genetic data to protect personal autonomy in the genomic age.