

LAW, BIOETHICS AND THE CURRENT STATUS OF OWNERSHIP, PRIVACY, INFORMED CONSENT IN THE GENOMIC AGE

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The rise of biobanks including the related databases containing increasing amount of health information are now commonplace – found on every continent of the globe including Antarctica. Common though they may be, legal and ethical issues for collecting, storing and using the associated health/genetic information continue to perplex clinicians, researchers, law enforcement, and the lay public alike. For example, one's image or likeness is copyrightable, but not one's genome. Yet billions of dollars are being made from patented genes, patented species, private databases, and human tissues. Several health care systems now collect human DNA samples from patients through "opt-out" programs, and vast collections of DNA are being assembled without compensation to donors. Now that whole genome sequencing is becoming more affordable, the bioinformatics community is rightly asking about its enduring obligations and responsibilities vis a vis genetic ownership, residual rights, privacy, and informed consent. And that's just in the USA. Many issues are magnified when material or data are intended to cross national borders. This workshop is designed to unpack many of the issues in pragmatic detail – hopefully dispelling certain myths while offering cautionary reminders about legal and ethical obligations. The two co-chairs will lead in-depth discussion and facilitate small group exercises to emphasize these issues. A particular highlight will be a mock “House of Commons” debate where workshop participants will be asked to take positions, ask questions, and vote with their feet. In other words, this workshop is meant to be provocative, user-friendly and skill enhancing.

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