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The Dynactome: Mapping Spatio-Temporal Dynamic Systems in Humans

Integrated GE³LS Research

Ethical issues and guidelines relating to the cross-jurisdictional use of human tissues and genetic information

GE³LS Project Leaders

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Summary

The GE³LS project team is examining ethical questions relating to the use of human tissues and genetic information, and ensuring confidentiality and protection of research subjects' privacy. A critical review of consent documents from China, and evaluation of conformity with Canadian laws and guidelines set forth in Canada's Tri-Council Policy Statement, Ethical Guidelines for Research Involving Humans, as well as international guidelines (e.g., International Ethical Guidelines for Biomedical Research Involving Human Subjects (Council for International Organizations of Medical Sciences/World Health Organization) and the Declaration of Helsinki (World Medical Association)) will be performed. Where nonconformities exist, the team will develop and implement an enhanced consent form for future donors to the biobank from which this project obtains its human tissue samples.

In addition, international research guidelines, including those mentioned above, will be assessed with respect to how they address biobanking studies, culminating in a review that details ways that genomics and proteomics researchers can deal with different international research guidelines in this area. The finished product will examine topics such as informed consent, standards for external review, recruitment of participants, and cultural challenges related to consent. The assessment will uncover where these guidelines are uniform and where they diverge, and highlight problems associated with this in relation to international research, particularly with the 'Dynactome' project. We will also study problems that arise when a standard is included on one or more documents but omitted on others.