



**University  
of Victoria**

Graduate Studies

Notice of the Final Oral Examination  
for the Degree of Master of Public Administration

of

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BA (Hons) (University of Calgary, 2016)

**“Governing Cross-Border Sharing of Genetic Data:  
A New Border Frontier”**

School of Public Administration

Friday, January 10, 2019

9:30 A.M.

Human and Social Development Building  
Room A373

Supervisory Committee:

Dr. Emmanuel Brunet-Jailly, School of Public Administration, University of Victoria (Supervisor)  
Dr. Helga Hallgrímsdóttir, School of Public Administration, UVic (Member)

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Dr. Oliver Schmidtke, Department of Political Science, UVic

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Dr. Tim Pelton, Department of Curriculum and Instruction, UVic

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## **Abstract**

Since the sequencing of the first human genome, nations have relied on collaborations with foreign and non-state actors to conduct genomics research and deliver clinical benefits to citizens. Genomics research has the potential to one day cure and prevent some of the most devastating diseases and disorders known to humans. In order to continue on this exciting trajectory of medical discovery, researchers must have access to large and diverse sets of genetic data. Currently in British Columbia, public-private partnerships are developing under projects such as the BC Superclusters to solve resource challenges and remain at the forefront of genomic research and precision medicine.

The information contained within an individual's DNA is arguably the most intimate form of information which uncovers a person's past, present and future. Such information is valuable not only to medical researchers and health care providers but also law enforcement, private for-profit organizations, insurance providers, financial institutions and employers. The risk of misuse and discrimination resulting from the inappropriate sharing of genetic data poses serious risks to human rights. Additionally, rapid advances in technology have enabled the digitization and near instantaneous sharing of personal information creating a novel environment for cross-border sharing. Data breaches and the abuse of citizen data by organizations such as Facebook, Cambridge Analytica and a number of retailers, and financial institutions has brought public awareness to the mass collection of data and the lack of infrastructure to manage these new developments.

In light of the benefits to sharing genetic data and the potential risks, clear and effective frameworks must be in place to enable the safe management of data that preserves the privacy of individuals and enables valuable data sharing between organizations around the world. Internationally, various approaches are utilized to address the sharing of personal information, some more restrictive while others more permissive. The primary problem this thesis seeks to explore is the challenge of governing genetic data in a manner that preserves privacy, autonomy and supports appropriate access between organizations, with a particular focus on cross-border data sharing.

## **Methodology and Methods**

This thesis was a qualitative study that employed a human rights framework outlined in the UNESCO Declarations. A review of grey, academic and legal literature was conducted to identify governance mechanisms and frameworks employed for the management of genetic data. The results from this review informed which cases would be most appropriate to conduct a comparative case study analysis. Three distinctly different governance models employed by the European Union (EU), China and a non-for-profit international consortium known as Global Alliance for Genomics and Health (GA4GH) were selected for further analysis. Additional research was conducted on each case study using primary and secondary sources of data. Primary sources of data included interviews with those related to each case study model, provincial and federal governments; subject matter experts in privacy, genomics and legal scholarship.

To address the relationship between data and cross-border sharing, a border theory lens was applied to gain a nuanced understanding of how to best manage data in extra-territorial spaces created by technology. This was achieved through border seminars, interviews and reviewing border theory scholarship.

### **Key Findings**

The research indicates that governance mechanisms exist in the form of declarations, guidelines and principles established by international non-governmental organizations which provide a human rights framework for the collection, use and disclosure of genetic data. However, the operationalization of such principles within jurisdictions varies with mixed results. While various bodies contribute to the regulation of data sharing, research suggests that the state plays a central role in the governance of genetic data which is achieved primarily through legislation.

Two common legislative approaches utilized are either omnibus privacy legislation which addresses the use of all personal data or sector specific legislation which only addresses personal health information. Within these frameworks, genetic data may be singled out as “exceptional” or have a stand-alone act stipulating specific practices around the collection, use and disclosure of genetic data. A key consideration for determining which approach is the most appropriate for a jurisdiction is consideration of context such as culture, community, health care system, legal structure, and geography.

Genetic data as a case study for border theory suggests that a re-bordering and de-bordering may be occurring simultaneously. Legislation as a governance mechanism creates new borders around genetic data which may contain provisions for sharing thus also contributing to a de-bordering. Within this approach, states may utilize a territorial approach limiting the sharing of genetic data to the physical boundary lines of the state or they may utilize a functional approach that enables the cross-border flow of genetic data through principled sharing in agreements or legislation. Functional borders may be more conducive to facilitating valuable data sharing for research and health care than territorial borders while still providing privacy protection.

Based on the research findings, due to the complexities of genetic data and the requirement to link with other forms of personal data to conduct analysis, omnibus legislation such as the EU’s General Data Protection Regulation may be the most effective approach to appropriately protect privacy while remaining adaptive to the continuous evolution of genetic data usage. However, when considering BC’s context, health sector specific legislation may be the most appropriate fit within a federated Canadian system that possesses public and private sector privacy legislation. Finally, current aspects of BC’s privacy framework may create sharing challenges due to the territorial nature of the data residency provision under the Freedom of Information and Protection of Privacy Act. The movement towards a more functional model that relies on agreements and legal sharing provisions may safely remove barriers without endangering privacy.