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# THE CREATION OF UNIVERSITY INTELLECTUAL PROPERTY: CONFIDENTIAL INFORMATION, DATA PROTECTION, AND RESEARCH ETHICS

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# THE CREATION OF UNIVERSITY INTELLECTUAL PROPERTY: CONFIDENTIAL INFORMATION, DATA PROTECTION, AND RESEARCH ETHICS\*

*Mark Perry and Margaret Ann Wilkinson\*\**

## ABSTRACT

Protection of commercial confidences is both required as part of the intellectual property provisions of current trade agreements and routinely prerequisite for achieving patent protection. This paper discusses the protection of such commercial confidences and the relationship of this protection with the statutory regime in Canada of personal data protection, but does so within the specific context of an examination of these matters in light of the governance of the processes of research conducted in universities. The nexus of university research and commercial research occurs frequently—for example, in the area of the development and testing of drugs in Canada. The paper demonstrates that there are problems in bringing together and integrating the law of protection of confidential information and personal data protection with university practices in Canada. We analysed the research policies of research-intensive public universities across Canada; the Tri-council policy statement, which governs their research practices; and the legal requirements applicable to the universities in Canada's provinces. The paper demonstrates that there is a disjunction between the law, university policies, and Tri-Council policy.

## RÉSUMÉ

Une protection des secrets commerciaux est requise tant au chapitre des dispositions sur la propriété intellectuelle dans les ententes commerciales que comme préalable courant à l'obtention d'une protection par brevet. Cet article traite de la protection des secrets commerciaux et de son rapport avec les mesures législatives du Canada en

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matière de protection des données personnelles. Il examine toutefois cette question dans le contexte particulier de la conduite des activités de recherche menées dans les universités. Il existe souvent une jonction entre la recherche universitaire et la recherche commerciale, par exemple, dans le domaine du développement et de l'essai des médicaments au Canada. L'article démontre que des problèmes surgissent lorsqu'il faut rapprocher les lois sur la confidentialité des renseignements et la protection des données personnelles et les intégrer aux pratiques qui ont cours dans les universités au Canada. Nous avons analysé les politiques de recherche des universités publiques canadiennes axées sur la recherche, la politique des trois Conseils qui régit leurs pratiques en matière de recherche et les exigences juridiques applicables aux universités dans les provinces canadiennes. L'article montre qu'il y a désaccord entre la législation, les politiques universitaires et la politique des trois Conseils.

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## 1.0 INTRODUCTION

This article is concerned with the protection of commercial confidences in the process of university research, whether restraints on the generation and use of information are by confidential information, data protection, or ethics review requirements.<sup>1</sup> This question is pressing in light of the increasing recourse to public–private partnerships taking place in Canada, which frequently include universities. This article therefore examines the legal position of commercial confidences in the light of recent developments in personal data protection legislation and university ethics processes. It also describes the results of an empirical review of university practices in this respect undertaken in 2006. The study addresses not only the legal position of confidentiality in the research process but also the way in which regulation, policy, and practices relating to confidentiality actually appear to be impacting the conduct of research, including health research, in universities across Canada.<sup>2</sup>

### 1.1 The Protection of Commercial Confidences

For some time the courts have held that a contractual provision requiring that a confidence be kept will be enforceable as between the parties to the contract.<sup>3</sup> Over the past decades the courts have also developed a remedy<sup>4</sup> such that a confider may have an action against a confidant who discloses information that was: (1) secret at the time it was initially disclosed to the confidante; (2) given to the confidante in confidence, and in a situation where (3) the confider suffered as a result of the disclosure and the confidante derived a benefit.<sup>5</sup> The courts have protected these sorts of confidences particularly in the commercial context; however, the principles have been applied to health information, as evidenced by the decision in *Peters-Brown v. Regina District Health Board*,<sup>6</sup> where the plaintiff succeeded on the grounds of breach of confidence as well as contractual breach.

### 1.2 Governance of the Processes of University Research

While developments have been occurring in the legal protection of business confidences, the governance of the processes of university research has become increasingly standardized across campuses in Canada. As the major funders of research, all three of Canada's major federal administrative funding bodies, the Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council (SSHRC), have been concerned to safeguard the rights of the subjects of research and to regulate the conduct of researchers funded with their public funds. This concern has most recently been expressed through the 1998 creation of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*.<sup>7</sup> This policy is administered through the research ethics boards of the universities receiving funding from any of these federal funding bodies.

### **1.3 Protection of Personal Data in Canada**

At roughly the same time as the federal funding bodies have been integrating their approaches to ethics in the university context and the courts have enshrined the common law action for breach of confidence, both federal and provincial legislators have been grappling with questions about an individual's control over his or her personal information and the need to ensure that personal information is secured. As well, both courts and legislatures have grappled with the related but separate issues of privacy protection.<sup>8</sup> Personal data protection has been gradually enacted through legislation across Canada since 1977. Personal data protection, although related to privacy protection, is not privacy law.<sup>9</sup> Rather than protecting secrets held by individuals, as protection of privacy as a tort is designed to do, personal data protection is probably more closely related to principles of confidentiality; however, it is distinct from each. Personal data protection laws are intended to provide legal controls over the ways in which organizations can deal with an individual's personal data. They assume that information about individuals has not been held private by those individuals (where privacy law would reinforce the individuals' desires for privacy), but instead has made its way into the hands of organizations. Unlike the law of protection of confidentiality, or contracts providing protection for confidences between the parties to the contract (such as a non-disclosure agreement), legislated personal data protection controls apply regardless of whether the information was secret or non-public in the first place and regardless of an individual's awareness that the information was being collected.

### **1.4 Potential Problems in Integrating the Law of Protection of Confidential Information, Personal Data Protection, and University Practices Governing the Conduct of Research**

Since the laws on personal data protection and the legal protection of confidential information have been developing separately, there is potential for conflict as confidential information law is intended to give protection to any information held in confidence by organizations and personal data protection legislation gives individuals control over information about themselves held by those same organizations.<sup>10</sup> On the other hand, because personal data protection is entirely statute driven, it is possible that the legislatures anticipated and have resolved potential conflicts between personal data protection and commercial confidences. It is also possible that the legislatures have anticipated and resolved potential conflicts in these areas that can arise in the context of university research. One of the objects of this research was to determine whether such conflicts have been resolved by the lawmakers or whether such potential problems persist.

### **1.5 Related Literature**

Very little research even tangentially connected to this topic has been published.<sup>11</sup> There *has* been an increasing interest among some funders and researchers in enhancing the development of efficiency in the research process by sharing data sets

among researchers. To date, of the three major Canadian federal research funding bodies, only SSHRC has created an official policy aimed at implementing this kind of data sharing.<sup>12</sup> At the same time as the study for this paper was in progress, another study in a related area was initiated by then graduate student Carol Marie Perry, who investigated the data-archiving practices and concerns of SSHRC grant recipients.<sup>13</sup> Overall, Perry found that the researchers surveyed agreed with the *concept* of a national data archiving strategy, in line with current SSHRC policy,<sup>14</sup> but noted that a large gap remained between this recognized need to archive and the researchers' actual practices. The researchers had concerns about their abilities to comply with data archiving policies.<sup>15</sup> Particularly germane to this research was Perry's finding that some researchers expressed concerns about their ethical and legal obligations to their research subjects, resolving issues of confidentiality, and discrepancies between national and institutional policies.<sup>16</sup>

The other prominent publication in this area is the CIHR's *Best Practices for Protecting Privacy in Health Research*.<sup>17</sup> This document sets out a 10-element CIHR best practice, which is intended to guide researchers conducting health-related research in Canada with respect to their responsibilities to protect the privacy of their research subjects.<sup>18</sup>

Many articles have been published regarding health research ethics, which represent two distinct approaches in the wider literature. The first stream philosophically explains why there is a need to behave ethically while conducting health research, but omits any discussion of the legal requirements surrounding health research ethics.<sup>19</sup> The second stream focuses on the practical requirements of conducting health research. These articles, generally, provide overviews of the policies and laws that govern health research and the researchers' and subjects' interests in protecting confidential information.<sup>20</sup> While these articles acknowledge the legal parameters surrounding health research ethics, the extent of their discussion tends to be a brief primer on the potential application of the *Personal Information Protection and Electronic Documents Act* (PIPEDA) to health research without sometimes even the necessary discussion of the application of provincially enacted personal data protection legislation to health research.

## **2.0 THE LEGAL POSITION OF UNIVERSITY RESEARCH WITH RESPECT TO PROTECTION OF PERSONAL DATA AND COMMERCIAL CONFIDENCES**

### **2.1 Public Sector Access and Personal Data Protection Legislation Examined**

As mentioned, in Canada, all 14 Canadian jurisdictions have legislated in the area of public sector personal data protection. This personal data protection legislation has universally come to take the form of the creation of an administrative regime. Generally, this legislation is included in a package providing exceptions to the legislation creating a right to access information held by government bodies and,

depending on the jurisdiction, this concept of government bodies may or may not be legislated to include universities. In no case does personal data protection legislation in this country involving public sector organizations take the form of creation of a tort. Under these public sector regimes, there is no right given to an individual to recover money (damages) from the organizations governed by the legislation, but the organizations are subject to administrative sanctions, such as publication of their identities and errors.<sup>21</sup>

On the other hand, the personal data protection statute with the most impact on the private sector in Canada is the federal *Personal Information Protection and Electronic Documents Act*<sup>22</sup> (PIPEDA) and it ultimately *does* allow aggrieved individuals to sue for damages if the statute is breached by the organization charged with the duties under the statute.<sup>23</sup>

PIPEDA governs all organizations engaged in “commercial activities” in Canada<sup>24</sup> unless there is a provincial enactment that the federal government has deemed to be substantially similar. Quebec,<sup>25</sup> Alberta,<sup>26</sup> and British Columbia<sup>27</sup> have their own private sector personal data protection laws that have been deemed to be substantially similar to PIPEDA.<sup>28</sup> PIPEDA also governs all federally regulated private sector organizations in Canada and those private sector organizations anywhere in Canada that disclose personal information across provincial or national boundaries.<sup>29</sup> Most commercial entities are becoming familiar with PIPEDA (and, in some cases, its provincial equivalents).

Despite the fact that most universities in Canada are not government-owned,<sup>30</sup> PIPEDA is not the statute that generally governs universities with respect to personal data protection. Universities are governed by provincial personal data protection legislation from their respective provinces. One finding of this research is that universities, which are generally governed by provincial legislation, have been treated in different ways by the various legislatures of the provinces and territories.<sup>31</sup>

Universities do not currently exist in Canada’s territories to the same extent that they do in Canadian provinces. However, Nunavut’s *Access to Information and Protection of Privacy Act*<sup>32</sup> applies to its Nunavut Arctic College<sup>33</sup> and the regulations to the Northwest Territories’ *Access to Information and Protection of Privacy Act*<sup>34</sup> list several colleges.<sup>35</sup> Of the personal data protection statutes in the territories, only the Yukon’s legislation makes no mention of institutions of higher learning.<sup>36</sup> Because institutions of higher learning are expanding in the territories, and much research is being conducted involving those institutions, this research includes analysis of the legislation of the territories.

In two provinces, New Brunswick and Prince Edward Island, and in the Yukon Territory, the public sector personal data protection legislation does not apply to universities.<sup>37</sup> In these three jurisdictions, then, there is no statutory framework that overrides the legal protection of business confidences, and non-disclosure agreements pertaining to university research would be fully enforceable.

In Saskatchewan, two pieces of public sector personal data protection legislation exist, the *Freedom of Information and Protection of Privacy Act* (FIPPA (Saskatchewan))<sup>38</sup> and the *Local Authority Freedom of Information and Protection of Privacy Act* (LAFIPPA).<sup>39</sup> FIPPA (Saskatchewan) applies across the province but does not mention universities in its application.<sup>40</sup> LAFIPPA expressly does not apply to information to which FIPPA (Saskatchewan) applies,<sup>41</sup> but does apply to local government.<sup>42</sup> LAFIPPA covers university research.<sup>43</sup>

Ontario, which also has separate statutes governing provincial organizations<sup>44</sup> and municipal organizations,<sup>45</sup> has characterized universities differently from the way its counterpart in Saskatchewan has done—in Ontario, universities have been included in the legislation governing provincial entities. Moreover, Ontario has included a provision exempting university research from the purview of its public sector personal data protection legislation.<sup>46</sup>

British Columbia, Alberta, Manitoba, and Newfoundland and Labrador each have one statute governing all personal data protection in the public sector—and, in each case, university research is specifically exempted from its application.<sup>47</sup>

In Quebec, the public sector personal data protection legislation includes universities but excludes certain types of research—for example, “scientific research.”<sup>48</sup>

In Nova Scotia, the Northwest Territories, and Nunavut,<sup>49</sup> the public sector personal data protection legislation applies to universities and does not contain any exemption for university research.

Therefore, in Nova Scotia and Saskatchewan (as in the Northwest Territories and Yukon if there were universities), public sector personal data protection legislation governs the collection, use, and disclosure of information collected for university research. Public sector personal data protection legislation applies in Quebec to university research that is “non-scientific” (and, as will be discussed below, to health research in Manitoba). In the other jurisdictions of Canada, universities do not need to have regard to personal data protection legislation in respect of university research, either because the university itself is not subject to personal data protection legislation or because there are specific exemptions for university research in the personal data protection legislation to which the university is subject (see Figure 1).

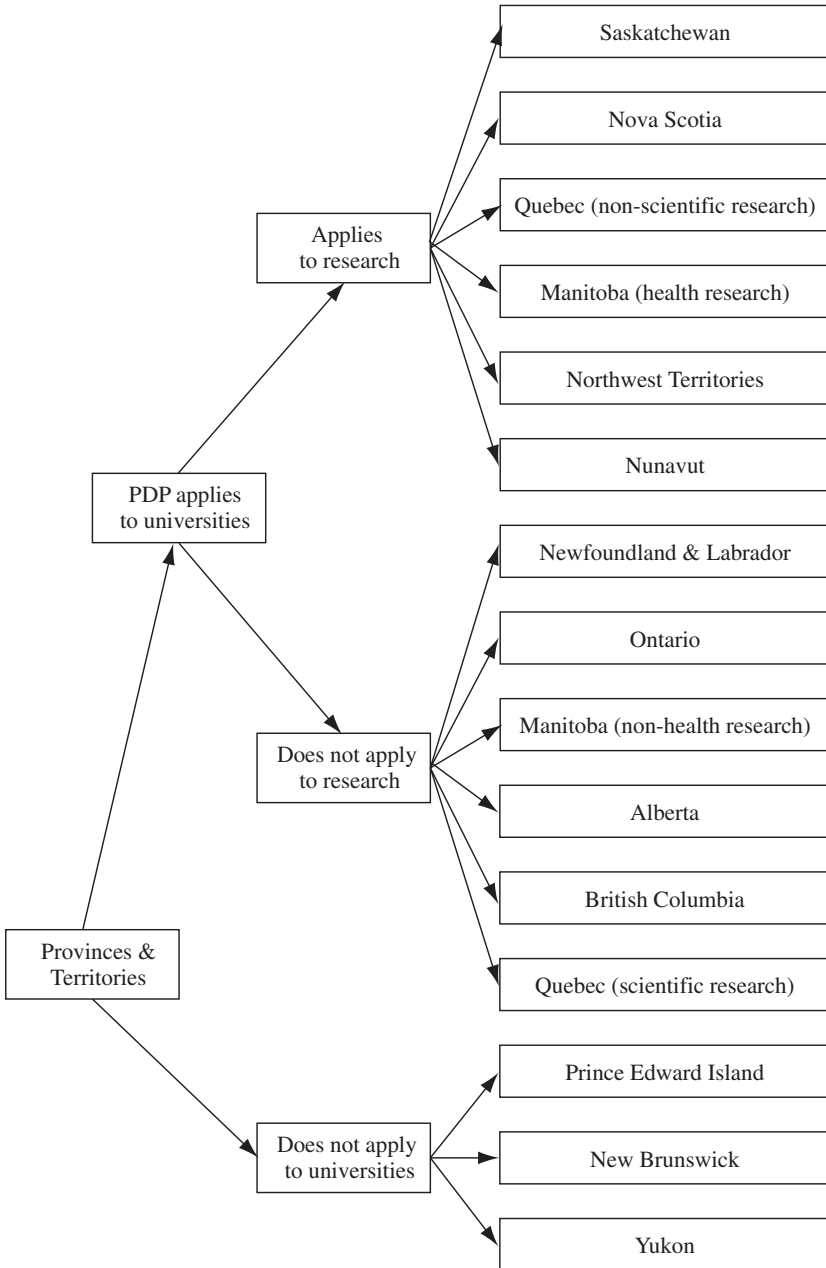
## **2.2 The Effect of Personal Health Information Statutes on University Research**

As mentioned above, when moving personal data protection in the private sector to legislation, the federal government expressly left room for provinces and territories to create “equivalent” legislation. It did so by decreeing that, where the federal government has approved certain legislation as being equivalent to the PIPEDA, that provincial legislation replaces the federal legislation.

A recent area of provincial activity in this respect has been the creation, by certain provinces, of special sectoral health legislation to replace, in respect of health, both their own public sector personal data protection legislation and the federal PIPEDA.



**Figure 1 The Application of Personal Data Protection Legislation to University Research in Canada**



As far back as 1992, the Supreme Court of Canada stated that, although medical records are the property of the doctor or hospital that compiles them, the patient has a right to access them.<sup>50</sup> The ruling also stated that the right to access is not unlimited, but that the physician must have reasonable grounds for refusing to disclose. Such a reasonable ground would be to prevent the patient from experiencing further harm as a result of the disclosure.<sup>51</sup> However, the proliferation of personal data protection regimes governing public and private sector organizations, the increased intermingling of private and public sector organizations in the provision of health care, and professional medical concerns have prompted some provinces to create unique statutes for health designed both to accommodate personal data protection principles<sup>52</sup> and to attempt to ensure that medical professionals have the medical history they need to treat each patient properly.<sup>53</sup> Some of these laws also allow aggrieved individuals to sue for damages if the statutes are breached by the organization or health care providers.<sup>54</sup>

Ontario's *Personal Health Information Protection Act*<sup>55</sup> has received recognition from the federal government and does replace PIPEDA in the health context. In three other provinces, Alberta,<sup>56</sup> Saskatchewan,<sup>57</sup> and Manitoba,<sup>58</sup> the province has passed sectoral health legislation governing personal data protection in the public and private sectors, but the federal government has not deemed this legislation to be equivalent to PIPEDA. In Ontario, Alberta, and Manitoba, the universities are covered by public sector personal data protection legislation that provides exemptions for university research. It was important for this research, however, to examine whether the passage of the sectoral health personal data protection legislation "recaptured" some aspects of university research in the purview of the new personal data protection regimes for health.<sup>59</sup>

In Alberta and Ontario, the health sector personal data protection legislation does not apply to universities. In these two provinces, then, the position that university research is not covered by personal data protection legislation is not changed by the passage of the provincial sectoral personal health data protection legislation.

Saskatchewan's LAFIPPA, as discussed above, applies to universities and covers university research, but, according to the more recent Saskatchewan HIPA, does not apply to health information held by a local authority that is a trustee and, therefore, covered by the HIPA.<sup>60</sup> However, if the local authority is not defined as a trustee according to the *Health Information Protection Act*, then LAFIPPA continues to apply to all university research, including health-related research.<sup>61</sup> In either case, all university research in the province of Saskatchewan is covered by personal data protection legislation and thus the legal protection of confidences related to any university research in Saskatchewan is overridden by personal data protection legislation.

On the other hand, although Manitoba's *Freedom of Information and Protection of Privacy Act* (FIPPA) exempts research from the application of the Act to universities (as discussed above), its newer *Personal Health Information Act* (PHIA) does cover universities (see s. 1) and does not contain an exemption for research.<sup>62</sup> Consequently, in Manitoba, PHIA governs the collection, use, and disclosure of health-related information collected for university research.

**Table 1 Personal Data Protection Legislation by Jurisdiction\***

Jurisdiction	Relevant enactments
Alberta	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, R.S.A. 2000, c. F-25.</li> <li>• <i>Health Information Act</i>, R.S.A. 2000, c. H-5.</li> <li>• <i>Personal Information Protection Act</i>, S.A. 2003, c. P-6.5.</li> </ul>
British Columbia	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, R.S.B.C. 1996, c. 165.</li> <li>• <i>Personal Information Protection Act</i>, S.B.C. 2003, c. 63.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Manitoba	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, S.M. 1997, c. 50.</li> <li>• <i>Personal Health Information Act</i>, C.C.S.M. 2005, c. P33.5.<sup>a</sup></li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
New Brunswick	<ul style="list-style-type: none"> <li>• <i>Protection of Personal Information Act</i>, C.S.N.B. 1998, c. P-19.1.</li> <li>• <i>Right to Information Act</i>, S.N.B. 1978, c. R-10.3.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Newfoundland & Labrador	<ul style="list-style-type: none"> <li>• <i>Access to Information and Protection of Privacy Act</i>, R.S.N.L. 2002 c. A-1.1.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Northwest Territories	<ul style="list-style-type: none"> <li>• <i>Access to Information and Protection of Privacy Act</i>, S.N.W.T. 1994, c. 20.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Nova Scotia	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, R.S.N.S. 1993, c. 5.</li> <li>• <i>Municipal Government Act, Part XX—Freedom of Information and Protection of Privacy</i>, C.S.N.S. 1998, c. 18.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Nunavut	<ul style="list-style-type: none"> <li>• <i>Access to Information and Protection of Privacy Act</i>, S.N.W.T. 1994, c. 20 (as amended by S. Nu. 2003, c. 31, s. 2).</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Ontario	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, R.S.O. 1990, c. F.31.</li> <li>• <i>Municipal Freedom of Information and Protection of Privacy Act</i>, R.S.O. 1990, c. M. 56.</li> <li>• <i>Personal Health Information Protection Act</i>, R.S.O. 2004, c. 3.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>

**Table 1 Continued**

Jurisdiction	Relevant enactments
Prince Edward Island	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, R.S.P.E.I. 1998, F-15.01.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Quebec <sup>b</sup>	<ul style="list-style-type: none"> <li>• <i>An Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information</i>, R.S.Q. 2005, c. A-2.1.</li> <li>• <i>An Act Respecting the Protection of Personal Information in the Private Sector</i>, R.S.Q. 2005, c. P-39.</li> <li>• <i>Archives Act</i>, R.S.Q. 1983, c. A-21.1.</li> </ul>
Saskatchewan	<ul style="list-style-type: none"> <li>• <i>Freedom of Information and Protection of Privacy Act</i>, S.S. 2000, c. F-25.</li> <li>• <i>Health Information Protection Act</i>, S.S. 1999 c. H-0.021.</li> <li>• <i>Local Authority Freedom of Information and Protection of Privacy Act</i>, R.S.S. 1990-91, c. L-27.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Yukon	<ul style="list-style-type: none"> <li>• <i>Access to Information and Protection of Privacy Act</i>, R.S.Y. 2002, c. 1.</li> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> </ul>
Federal	<ul style="list-style-type: none"> <li>• <i>Personal Information Protection and Electronic Documents Act</i>, S.C. 2000, c. 5.</li> <li>• <i>Privacy Act</i>, R.S.C. 1985, c. P-21.</li> </ul>

\* Recall that PIPEDA applies in respect of personal data information to every private organization that collects, uses, or discloses in the course of commercial activities (*Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5, s. 4) where transfers of data outside the province are involved. In this table, PIPEDA is only listed for those provinces that do not have provincial, private sector personal data protection legislation designated by the federal government as equivalent *within the province* to PIPEDA. We are showing legislation prior to 2006.

<sup>a</sup> The newest amendment to this legislation came into force as of May 1, 2010. This table lists the versions of legislation used in the original study in 2006.

<sup>b</sup> Also of importance, the already mentioned *Quebec Civil Code*, and the *Quebec Charter of Rights and Freedoms*.

The development of sectoral personal data protection legislation in health therefore changes the position of research in Manitoba's universities to include research in personal data protection legislation if health research is involved, but not otherwise. Non-disclosure agreements in Manitoba will thus be unenforceable with respect to university research involving health, but will otherwise be enforceable (see Figure 1, above). These conclusions are supported, as discussed, by examination of the pieces of legislation applicable to each province and territory set out in Table 1.

### **2.3 Personal Data Protection Legislation and Governance of the University Research Process**

As described at the outset, throughout Canada, university research ethics boards regulate the research conducted by researchers by enforcing against those *researchers* ethics policies that follow the *Tri-Council Policy Statement*. On the other hand, personal data protection legislation provides *individuals* with control over information that can identify the individual and is held by either public or private organizations. Consequently, where research is conducted in a jurisdiction where it is subject to personal data protection legislation, that legislation will govern the collection and protection of research data about living and recently deceased human subjects.<sup>63</sup> This applies to university research ethics boards and researchers in Nova Scotia, Saskatchewan, Manitoba, and Quebec, and will apply to those in the Northwest Territories and Nunavut as university institutions develop there. If researchers in these jurisdictions are following their ethics policies and have received the approval of the research ethics review boards, but the policies and decisions of those boards do not align with the applicable personal data protection legislation, then these researchers and their university institutions will not be fulfilling their legal data protection requirements. As identified at the outset, one object of this research was to examine the extent to which problems exist in this regard.

## **3.0 THE GOVERNANCE OF UNIVERSITY RESEARCH IN CANADA**

### **3.1 Does the Tri-Council Policy Statement Reflect the Legal Requirements Applicable in the Various Provinces?**

One way to ensure that universities have no problem meeting their legislative requirements in research through the administration of their research ethics boards is to ensure that the policies these boards are administering are in express compliance with relevant legislation. A starting point for such compliance is clear, specific, and accurate acknowledgment of any applicable personal data protection requirements in the federal *Tri-Council Policy Statement*. The Statement was thus first analyzed from this perspective.

Of course, it would be helpful to universities where research *is* governed by personal data protection legislation to have the three leading Canadian research funding bodies indicate in the *Tri-Council Policy Statement* that such legislative requirements would affect the ability of the researcher to enter into legally enforceable non-disclosure agreements. Therefore, the Statement was closely examined to see whether such acknowledgment exists.

Even where universities are permitted to enter into legally enforceable non-disclosure agreements because the conduct of research is unaffected by personal data protection legislation, it would be possible for any or all of the three leading Canadian funding bodies to decide that funding research covered by non-disclosure agreements is not appropriate. If such a decision were made by any or all of these

funders, then any research done by universities that involved non-disclosure agreements would become ineligible for the funds distributed by the funding body or bodies that had made that policy decision. The *Tri-Council Policy Statement* was also investigated, therefore, to see whether it reflected any such policy decision.

Two articulated goals of the *Tri-Council Policy Statement* are to promote the ethical conduct of research involving human subjects and to harmonize the ethics review process conducted by research ethics boards across Canadian universities.<sup>64</sup> The policy is based on a moral imperative, rather than any legal obligation: to have a measure of respect ingrained in the methods of conducting research on human subjects. This includes a respect for human dignity, for free and informed consent, for vulnerable persons, respect for privacy and confidentiality, justice and inclusiveness, and a balancing of the harms and benefits of research.<sup>65</sup> The policy differentiates ethics from the law in that laws compel obedience to behavioural norms, while ethics aim to promote high standards of behaviour through an awareness of values. Even though it is noted that ethics cannot pre-empt the application of law, they may deal with situations beyond the law's scope and direct its future development.<sup>66</sup>

Article 1.1 of the *Tri-Council Policy Statement* requires that all research proposals for research on human subjects be submitted to a research ethics board. Section 1 sets out the required composition of these boards,<sup>67</sup> procedure for their meetings, and the approach they must take in assessing each research proposal.<sup>68</sup> Section 2 deals with informed consent.<sup>69</sup> Section 3 of the *Tri-Council Policy Statement* deals with privacy and confidentiality; the criteria that research ethics boards at all universities should use in evaluating research proposals are detailed in articles 3.2 to 3.6.

The introduction to section 3 provides:

Information that is disclosed in the context of a professional or research relationship must be held confidential. Thus, when a research subject confides personal information to a researcher, the researcher has a duty not to share the information with others without the subject's free and informed consent. Breaches of confidentiality may cause harm: to the trust relationship between the researcher and the research subject; to other individuals or groups; and/or to the reputation of the research community. Confidentiality applies to information obtained directly from subjects or from other researchers or organizations that have a legal obligation to maintain personal records confidential. In this regard, a subject-centred perspective on the nature of the research, its aims and its potential to invade sensitive interests may help researchers better design and conduct research. A matter that is public in the researcher's culture may be private in a prospective subject's culture, for example.<sup>70</sup>

Section 3 also states "privacy in research ... has been enshrined in Canadian law as a constitutional right and protected in both federal and provincial statutes,"<sup>71</sup> and that if a third party attempts to gain access, researchers must protect confidentiality "to the extent possible within the law." The policy does not explicitly cite any law governing these issues,<sup>72</sup> and the introduction to Section 3 speaks instead of the adoption of voluntary codes.<sup>73</sup> It claims that the research ethics board at institutions

“plays an important role in balancing the need for research against infringements of privacy and minimizing any unnecessary invasions of privacy.”<sup>74</sup>

Research ethics boards must approve a potential researcher’s interview procedures and must ensure that potential researchers have the free and informed consent of subjects. Furthermore, in approving research based on the collection of identifiable personal information, factors to be evaluated by research ethics boards include:

- (a) The type of data to be collected;
- (b) The purpose for which the data will be used;
- (c) Limits on the use, disclosure and retention of the data;
- (d) Appropriate safeguards for security and confidentiality;
- (e) Any modes of observation (e.g., photographs or videos) or access to information (e.g., sound recordings) in the research that allow identification of particular subjects;
- (f) Any anticipated secondary uses of identifiable data from the research;
- (g) Any anticipated linkage of data gathered in the research with other data about subjects, whether those data are contained in public or personal records; and
- (h) Provisions for confidentiality of data resulting from the research.<sup>75</sup>

The policy goes on to say that identifiable personal information should not be released in research results. Subjects have a right to know who will have access to identifying information and whether the information will be provided to the government, government agencies, research sponsor, or any other regulatory agency.<sup>76</sup> The use of secondary data, or records that could be held by the school or another agency after the research is complete, must also be approved by the research ethics boards. Again, the ability to use such data is based on the subject giving prior informed consent, and on the research ethics board’s approval.<sup>77</sup>

From the previous analysis, it can be seen that universities in Saskatchewan, Nova Scotia, Manitoba, Quebec, Nunavut, and the Northwest Territories find themselves in a different legislative climate than those in the other jurisdictions of Canada. The current *Tri-Council Policy* does not differentiate between the two situations or provide specific guidance with respect to either personal data protection or protection of commercial confidences in any legislative context. Thus, lacking any clear, specific, and accurate acknowledgment of the legal requirements universities face, the *Tri-Council Policy* may be as much contributing to problems as helping to overcome them.

Nor does the *Tri-Council Policy Statement* directly address the concept of research conducted in the context of non-disclosure agreements, neither acknowledging any inability to enter into such agreements for universities whose research is subject to personal data protection legislation nor articulating any policy at all with respect to research involving commercial non-disclosure agreements. On the other

hand, under the Policy, *any* aspect of handling a user's information, including withdrawals of consent to disclose, must be handled by research ethics boards. In other words, a non-disclosure agreement drafted between the researcher and any entity could, based on the language of the *Tri-Council Policy Statement*, limit a research ethics board's mandate.<sup>78</sup> It thus appears that despite the creation of the *Tri-Council Policy Statement*, researchers are left on their own to determine which law—provincial or federal—applies to their research and, indeed, which standards of ethical conduct will be applied to their research by the research ethics board at their institution.

### **3.2 Do University Research Policies Reflect the Legal Requirements Applicable in Their Provinces?**

#### **3.2.1 The Universities Studied**

Before collecting information concerning privacy and confidentiality for research involving humans at universities across Canada, we first defined the term “university” for the purposes of the study; the term needed to be defined more narrowly than “post-secondary institution.”<sup>79</sup> To begin, institutions that the SSHRC, Association of Universities and Colleges of Canada (AUCC), and Canadian National Site Licensing Project (CNSLP) (as it then was) considered to be universities were compared and combined, resulting in over 100 universities and affiliated colleges in Canada. The study population was then reduced by using the list of universities that participated in the 2006<sup>80</sup> *Maclean's* magazine university rankings.<sup>81</sup> This narrowed the study to institutions of a size most likely to participate in health-related federally funded research (and produced a list of 47 institutions, all of which had also appeared on the SSHRC, AUCC, and CNSLP listings). However, the Université du Québec's six institutions do not participate in the *Maclean's* rankings, but do participate in a significant amount of health-related research (as our examination of SSHRC grants awarded during the period indicated).

Therefore, the Université du Québec à Chicoutimi, à Montréal, à Rimouski, à Trois-Rivières, en Outaouais, and Télé-université were also included in our study. The Royal Military College in Kingston is a unique post-secondary institution in Canada, with its long history and place as part of the federal Department of National Defence, and it too was included in the study. Thus, this study examined 54 institutions from across Canada (see Table 2). From this list, each institution's ethics policy was acquired and then compared against the existing personal data protection legislation in that province. Further, we examined whether the ethics policies reflected the correct state of the law. We then looked at whether each policy contemplated issues involving confidentiality agreements and determined whether those agreements reflected the university's position in law. Finally, where personal data protection legislation was determined not to be applicable to the university's research environment, the ethics policies were examined to see whether they dealt in any way with non-disclosure agreements, whether such agreements were addressed anywhere on the university's website, and whether the ethics policy specifically referred to the *Tri-Council Policy Statement* as the sole source of its authority.



**Table 2 University Ethics Policies and Websites Examined**

<i>Province</i>	<i>Number of universities studied</i>	<i>Names of universities studied</i>
Newfoundland & Labrador	1	Memorial University of Newfoundland
Nova Scotia	6	Acadia University Cape Breton University Dalhousie University Mount Saint Vincent University Saint Francis Xavier University Saint Mary's University
Prince Edward Island	1	University of Prince Edward Island
New Brunswick	4	Université de Moncton Mount Allison University University of New Brunswick St. Thomas University
Quebec	12	Bishop's University Concordia University Université Laval McGill University Université du Québec à Chicoutimi Université du Québec à Montréal (UQAM) Université du Québec à Rimouski Université du Québec à Trois-Rivières Université du Québec en Outaouais Université du Québec : Télé-université Université de Sherbrooke
Ontario	17	Brock University Carleton University University of Guelph Lakehead University Laurentian University of Sudbury McMaster University Nipissing University University of Ottawa Queen's University Royal Military College of Canada Ryerson University University of Toronto Trent University University of Waterloo The University of Western Ontario University of Windsor York University

**Table 2 Continued**

<i>Province</i>	<i>Number of universities studied</i>	<i>Names of universities studied</i>
Manitoba	3	Brandon University University of Manitoba University of Winnipeg
Saskatchewan	2	University of Regina University of Saskatchewan
Alberta	3	University of Alberta University of Calgary University of Lethbridge
British Columbia	4	The University of British Columbia University of Northern British Columbia Simon Fraser University University of Victoria

**Figure 2 Relationship Between Personal Data Protection Legislation (PDP) and Non-Disclosure Agreements (NDAs) in University Research Throughout Canada**

	<i>NDAs mentioned with approval in university ethics policy</i>	<i>NDAs not mentioned (or actively discouraged) in university ethics policy</i>
<i>Jurisdiction where PDP applies to university research</i>	<i>Error</i> Inappropriate to enter into an NDA in this jurisdiction because the legislation will override any contractual or other legal protection of a business confidence involving personally identifiable data.	<i>No Error</i> Best approach by university in these jurisdictions is to prohibit the entering into of NDAs related to university research in order to avoid later legal action over breach of confidence.
<i>Jurisdiction where PDP does not apply to university research</i>	<i>No Error</i> Where PDP is not legally required, a university can encourage NDAs between researchers and private sector partners.	<i>Error</i> A university in a jurisdiction without applicable PDP legislation that also does not mention NDAs, may fail to provide appropriate safeguards for subjects through their own administrative policies and may also fail to encourage researchers to consider NDAs when they are available as a legal instrument.

### 3.2.2 The Challenge for the Universities

Canadian universities exist in two different legal environments with respect to personal data protection in research—those subject to personal data protection legislation and those not subject. Yet the *Tri-Council Policy Statement*, to which the universities all demonstrably deferred for guidance in these areas,<sup>82</sup> is silent on this matter and on the question of non-disclosure agreements. This leads to two possible types of error by Canadian universities in creating their own internal research governance: if they are subject to personal data requirements in research, they can fail to be in compliance with them; or, if they are not subject to personal data requirements, they can incorrectly believe themselves to be required to comply. Both these types of errors can lead to further misapprehension of the university's position with respect to the ability to enter into legally binding non-disclosure agreements (see Figure 2).

### 3.2.3 Did the Ethics Policies at Individual Universities Accurately Reflect Their Obligations for Personal Data Protection?

Overall, the privacy, personal data protection, and confidentiality matters addressed in the research ethics policies and the other documents examined were similar from university to university across Canada. All policies made reference to applying and following the *Tri-Council Policy Statement* and many dealt generally with notions of privacy, confidentiality, and data security. Generally, policies made a statement about the importance of respecting participants' confidentiality. Most policies provided that confidentiality should be guaranteed, except where participants give express consent to disclose their personal information. Participants' anonymity was also a concern in most policies, which provided that participants' identities should always remain anonymous except where consent to disclose one's identity is provided. Many policies also warned researchers to be careful of unusual or sensitive circumstances—for example, group interviews or focus groups, cultural concerns, data linkage, quoting interviewees, and where participants are recorded with audio or video devices. Policies recognized that in these circumstances, in order to comply with the requirements of the *Tri-Council Policy Statement*, full and informed consent must be given for each and every one of these activities, along with specific information about who would have access to the stored data and for how long.

The policies and sample consent forms all stated that the following information should be provided to potential participants when obtaining informed consent for participation in research:

- what personal information will be collected;
- who will have access to the personal information;
- how confidentiality and anonymity will be maintained;
- how data will be stored;

- how long data will be retained and whether it will be destroyed after a certain period; and
- how the research results will be published and disseminated.

On the other hand, few of the policies actually cited legislation.

Where universities ought to have cited personal data protection legislation, few did so—all of them in Quebec (see Table 3). Even in Quebec, none of the references were precise enough to identify the applicability of the legislation only to scientific research. On the other hand, a number of universities located in jurisdictions where the research process is not governed by personal data protection legislation incorrectly cited personal data protection in their research ethics policies (see Table 4). Thus, many Canadian universities were in error in creating the ethics policies that govern the research ethics boards at their institutions in one of two ways—those who are required to adhere to personal data protection legislation largely failed to acknowledge this in their ethics policies, providing compelling evidence that those boards would not be requiring researchers to adhere to appropriate laws in the conduct of their research;<sup>83</sup> quite a number of universities that were not required to make their research processes conform to any statutory personal data protection regimes mistakenly thought that they were. To the extent that universities are making this error, it may be presumed that their research ethics boards may be undemocratically (and unreviewably) holding the university's researchers to a standard that the legislature of the province has deemed inappropriate in the research context. Clearly there is a tension in universities, which are public bodies, because they need to adhere to requirements for access to information that do not apply in private sector relationships.<sup>84</sup>

Also, the ethics policies of the University of Windsor and the University of Alberta indicated that researchers should comply with all applicable privacy legislation in the jurisdiction where the information collection takes place. This is interesting because, in actual fact, provincial personal data protection legislation does not apply outside the boundaries of the province. The information in the hands of the researcher is bound by laws in the researcher's jurisdiction, and is, generally, not bound by those laws in the subject's jurisdiction (unless, of course, they are in the same jurisdiction). This distinction is clear because all these statutes have provisions such as the one in Ontario's *Freedom of Information and Protection of Privacy Act*, that the legislation "applies to any record in the custody or under the control of an institution."<sup>85</sup>

Given that Canada's universities made errors in both directions about the applicability of personal data protection to their situations, as expected, those same universities also err in their policies regarding non-disclosure agreements. Table 5 shows those universities that erroneously referred researchers to non-disclosure agreements despite the fact that the university is in a jurisdiction where university research is governed by personal data protection legislation and thus non-disclosure agreements involving information about personally identifiable subjects would not be legally enforceable. The vast majority of Canadian universities are located in jurisdictions

**Table 3 PDP Applies to Research**

	Number of universities studied in jurisdiction	Number of universities correctly citing legislation	Number of universities not citing legislation
Saskatchewan	2	0	2 (100%)
Nova Scotia	6	0	6 (100%)
Quebec (non-scientific)	12	4*	8 (66.67%)
Manitoba (health)	3	1 (PHIA)	2 (66.67%)

\* Not specifically saying the legislation applies only to non-scientific research.

**Table 4 Provinces Where PDP Does Not Apply to University Research**

	Number of universities studied in jurisdiction	Number of universities incorrectly citing legislation	Number of universities not citing legislation
British Columbia	4	0	4 (100%)
Alberta	3	1 (33%)	2 (66.67%)
Ontario*	18	2 (11%)	16 (89%)
New Brunswick	4	0	4 (100%)
Prince Edward Island	1	0	1 (100%)
Newfoundland & Labrador	1	1 (100%)	0

\* Note that most Ontario universities were correct for *early* 2006, because no part of university operations were covered then; however, the universities in general are now covered, but there are research exemptions. Effective June 10, 2006 universities were covered by the *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F.31, s. 2(2), following amendment by S.O. 2005, c. 28, Sched. F, ss. 1(1), 9(2).

where non-disclosure agreements in the context of university research are not affected by personal data protection legislation and thus would be legally enforceable. Despite this reality, as Table 6 demonstrates, virtually no universities alert their researchers to the potential of non-disclosure agreements through their websites or their university ethics policies. Again, it can be assumed that this lack of attention to non-disclosure agreements may be evidence that research ethics boards are not fully considering the effect of non-disclosure agreements on the research projects coming forward for their approval and consideration. It is interesting to note that those universities erring in the application of personal data protection legislation were not the same universities erring with respect to non-disclosure agreements.

**Table 5 NDA Unenforceable in Light of PDP Legislation Affecting Research**

	Number of universities studied in jurisdiction	NDA's inappropriately encouraged in ethics policy or on website	NDA's not mentioned or discouraged
Saskatchewan	3	0	0
Nova Scotia	6	0	0
Quebec (non-scientific)	12	2*	10
Manitoba (health)	3	0	0

\* Universities with links to NDA precedents provided.

**Table 6 NDA Legally Enforceable**

	Number of universities studied in jurisdiction	Number of universities encouraging NDA's in ethics policies or on websites	Number of universities inappropriately censuring NDA's on websites or in ethics policies
British Columbia	4	2 (50%)	0
Alberta	3	0	0
Ontario	18	2 (11%)	0
New Brunswick	4	1 (25%)	0
Prince Edward Island	1	0	0
Newfoundland & Labrador	1	0	0

#### 4.0 CONCLUSIONS FROM THIS RESEARCH

The major influence on the formation of the processes governing university research in Canada is the *Tri-Council Policy Statement* promulgated jointly by the National Science and Engineering Research Council, the Social Sciences and Humanities Research Council, and the Canadian Institute of Health Research. It is the single and only source cited by every one of the 54 university research policies examined. Its importance to the research community is also underscored by the findings of Carol Marie Perry's study of SSHRC researchers themselves. And yet, the *Tri-Council Policy Statement* does not reflect the legal requirements for personal data protection applicable in the provinces in which the universities affected are located. And, while the *Tri-Council Policy Statement* does not expressly preclude non-disclosure agreements, it does not warn those universities in provinces where university research is subject to personal data protection legislation that non-disclosure

agreements involving personal data will be legally unenforceable and does not assist universities in provinces where non-disclosure agreements will be legally binding by indicating to research ethics boards how such agreements are to be evaluated in the ethics approval process.

This review also highlights the inconsistent treatment of personal data in the university research process by the different jurisdictions in Canada. Saskatchewan has included university research in its personal data protection at the municipal level whereas Ontario, the only other province to have two separate statutes governing institutions separately at the municipal and provincial levels, has included universities in its *provincial-level* legislation but has exempted the research process in universities. Four provinces and two territories include both universities in their personal data protection legislation and at least some university research within the scope of that legislation. Four provinces, like Ontario, include universities in the scope of their public sector personal data protection legislation, but exempt university research entirely from the application of the statutes. And, finally, there are three jurisdictions that do not include universities within the scope of their personal data protection legislation at all: Prince Edward Island, New Brunswick, and the Yukon.

As various jurisdictions have created sectoral legislation governing health information, a new complexity has been introduced into the university research environment. While Ontario and Alberta have maintained the same position of exclusion with respect to university research in their personal health information statutes as they have in their public sector personal data protection legislation, and Saskatchewan has consistently maintained the opposite position in its personal health information legislation (health research in universities is covered) as it had in its public sector personal data protection legislation, Manitoba now takes a different position with respect to university research involving health (through its sectoral personal health information protection legislation) than it does about university research involving other personal data (which is not covered by personal data protection legislation).

It can also be seen from the information presented here, that the complex interplay between confidential information, personal data protection, and privacy is not well represented in university ethics review systems and policies. Neither is the relationship between the *Tri-Council Policy Statement* and federal and provincial legislation clearly specified, let alone implemented in a coherent way.

It should be noted that the Interagency Advisory Panel on Research Ethics released a draft of a revised *Tri-Council Policy Statement* for public consultation, which closed on June 30, 2009. The Panel then released a further revised version of the draft to the public in December 2009, on which comment concluded March 1, 2010. The Panel is currently preparing a final draft based on those comments for submission to the three funding agencies.<sup>86</sup> One of the self-proclaimed highlights is “[m]ore nuanced guidance about balancing confidentiality against legal or professional requirements or ethical consideration that may call for disclosure of information.”<sup>87</sup> However, the draft still does not address the complexities of either the distinctions, if any, between health and non-health research or the relationship be-

tween ethical considerations required by funding bodies and compliance with requirements imposed by law. It is still up to the individual researcher to consider the implications for his or her own particular research project beyond the need to satisfy the institutional research ethics board. This is not a happy state of affairs, because researchers are typically ill-equipped to venture into such analysis, which would detract from the purpose of the original funding. It also makes public-private sector partnerships involving university research all the more complicated and risk-laden.

It seems, however, that this is not a matter that can be sorted out solely through the efforts of the federal granting agencies—or solely through any efforts at the federal level. That university research is treated inconsistently across the country in provincial personal data protection statutes is a matter that can only be dealt with through provincial-level negotiation and lobbying.

It seems inappropriate that research conducted by universities in certain provinces<sup>88</sup> (Saskatchewan and Nova Scotia), and in some provinces on certain topics (scientific research in Quebec and health research in Manitoba), should provide the individual subjects of that research with statutory personal data protection and recourse to statutory complaints processes independent of the university, while the research conducted in other provinces<sup>89</sup> (or, in the cases of Quebec and Manitoba, on topics not coming within the purview of the personal data protection legislative oversight) should leave the subjects of that research with no recourse except institutional complaints within the sole jurisdiction of the universities involved.<sup>90</sup>

This research has also demonstrated how the lack of consistency in the application of personal data protection legislation to university research also creates an uneven playing field across Canada for those wishing to enter into non-disclosure agreements with universities in relation to research.

This broadens the concern over the inconsistency of personal data protection in the university research environment to involve not only the individual subjects of research but also the private sector organizations involved with, and often supporting, the research in universities. In jurisdictions where personal data protection legislation applies to university research (Nova Scotia, Saskatchewan, Quebec in respect of scientific research, and Manitoba in respect of health research), any non-disclosure agreement put in place between two parties will not be legally enforceable if it purports to govern the treatment of personally identifiable information. And yet, in other jurisdictions (and in Quebec with respect to non-scientific research and in Manitoba with respect to research not involving health information), non-disclosure agreements between university researchers and others will be enforceable. In the latter situation, it may be of concern that the existence or contemplation of such agreements is not an explicit or evident criteria included in the consideration of proposed research by university research ethics boards when such agreements or conduct, which would establish the ground for a breach of confidence action, will alone regulate the relationship in law between the researcher and a third party, whatever the attitude of the research ethics board toward that relationship. As



discussed above, the *Tri-Council Policy Statement* refers only obliquely to non-disclosure agreements—for example, art. 3.2 requires that a research ethics board must consider limits on disclosure when approval is sought, but does not give guidance to the boards about what is required for compliance.

Finally, this research amply demonstrates that these inconsistencies among the legal environments surrounding university research in different jurisdictions of Canada is confusing university policy-makers. Some universities seem unaware that they are subject to personal data protection legislation in respect of research. None of them articulate any knowledge of the implications that being subject to such legislation has on the ability of the researcher to enter into enforceable non-disclosure agreements, and several erroneously lead their researchers to non-disclosure agreement precedents as though such agreements would be enforceable in their circumstances. Other universities not subject to personal data protection in respect of their research provide information leading their researchers (and potential research subjects) to believe that they are. This type of error can be equally misleading. For example, in these circumstances, researchers otherwise familiar with how aspects of personal data protection legislation frustrate the ability to make legally enforceable non-disclosure agreements involving personally identifiable information may pass up legitimate opportunities to enter into research agreements involving non-disclosure agreements in reliance on the misinformation about the applicability of personal data protection legislation provided by their own institutions.

It is evident from the discussion above that these issues need to be addressed by the stakeholders—namely, the provincial and territorial legislatures, the Tri-Council, and the universities. This study has looked at the “gatekeepers” to much of the funded university intellectual property generation—namely, the research ethics boards and the requirements to comply with the *Tri-Council Policy Statement* and legislation. Clearly, individual researchers and private sector partners have not been canvassed in this study, but it is likely that they are currently unaware of the problems, or, even worse, actively misled by the guidance they are given.

## ENDNOTES

- <sup>1</sup> The research for this paper was carried out as part of a larger study undertaken for the Presidential Fund of the Social Sciences and Humanities Research Council of Canada over several years.
- <sup>2</sup> Now the Canadian Institutes of Health Research (CIHR) is the only federal body that funds health research, by a decision taken in 2009, but earlier all three of the tri-councils were funding health research (Department of Finance Canada, *Canada's Economic Action Plan: Budget 2009* at 270). After 2009, apart from specifically targeted joint research programs between agencies, “research that is primarily intended to improve health” or “clinical trials, with a health research orientation” or “research that is eligible under the mandate of CIHR” will not be eligible for consideration by the Social Sciences and Humanities Research Council of Canada (SSHRC), online: <[http://sshrc.ca/funding-financement/apply-demande/background-renseignements/selecting\\_agency-choisir\\_organisme\\_subventionnaire-eng.aspx](http://sshrc.ca/funding-financement/apply-demande/background-renseignements/selecting_agency-choisir_organisme_subventionnaire-eng.aspx)>. Similarly, after 2009, the Natural Sciences and Engineering Research Council of Canada (NSERC) would grant funding only to those health-related research

projects that had advancement of the natural sciences or engineering as their primary goal, with specific exclusions for vaccination research and health-related research that had progressed to the clinical trial stage; see NSERC, online: <[http://www.nserc-crsng.gc.ca/NSERC-CRSNG/Policies-Politiques/subjectevalHealth-sujetevalSante\\_eng.asp](http://www.nserc-crsng.gc.ca/NSERC-CRSNG/Policies-Politiques/subjectevalHealth-sujetevalSante_eng.asp)>.

- <sup>3</sup> An example of this, relating to the sale of a business, is *Hargraft Schofield LP v. Schofield*, [2007] O.J. No. 4400 (Sup. Ct. J.).
- <sup>4</sup> The Supreme Court of Canada has been reluctant to refer to confidential information in terms of property in a criminal law context (*R. v. Stewart*, [1988] 1 S.C.R. 963, 50 D.L.R. (4th) 1) and considers an action relating to confidential information more appropriately dealt with by a claim of breach of confidence. (*Cadbury Schweppes Inc. v. FBI Foods Ltd.*, [1999] 1 S.C.R.142, 167 D.L.R. (4th) 577). This treatment of confidential information may result from the fact that confidential information is more abstract than either an expression (addressed by copyright) or aspects of an invention (addressed by patent); on the other hand, some consider it no less a product of the mind than conventional forms of intellectual property; see M.A. Wilkinson, “Confidential Information and Privacy-Related Law in Canada and in International Instruments” in C. Carmody, ed., *Is Our House in Order? Canada’s Implementation of International Law* (Montreal: Queen’s McGill Press, 2010) 275 [“Confidential Information”].
- <sup>5</sup> Recall that, as matters of civil, rather than criminal, concern in the province of Quebec are governed under civil, rather than common, law, it is always the legislators who are concerned in the first instance with the creation of law for this province in civil matters. In the other jurisdictions of Canada, of course, the courts can elucidate principles of law on their own initiative; however, if there is subsequent legislation on the same point, the legislation will displace the common law initiative of the courts. In Quebec, being a civil law jurisdiction, a cause of action must be codified, and an exact codification for breach of confidence does not yet exist. See “Confidential Information,” *ibid.* at 295.
- <sup>6</sup> *Peters-Brown v. Regina District Health Board*, [1995] S.J. No. 609 (Sask. Ct. Q.B.).
- <sup>7</sup> Canada, Panel on Research Ethics, *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans* (Ottawa: Public Works and Government Services Canada, 2003), online: <<http://pre.ethics.gc.ca/english/policystatement/section3.cfm>> [*Tri-Council Policy Statement*]. There are ongoing attempts at a second revision of the *Tri-Council Policy Statement*, which will be discussed below.
- <sup>8</sup> M.A. Wilkinson, “Battleground Between New and Old Orders: Control Conflicts Between Copyright and Personal Data Protection” in Y. Gendreau, ed., *Emerging Intellectual Property Paradigm—Perspectives from Canada* [Queen Mary Studies in Intellectual Property] (Cheltenham, U.K.: Edward Elgar, 2008) 227-66; M.A. Wilkinson, “Privacy and Personal Data Protection: Albatross for Access?” in K. Adams & W.F. Birdsall, eds., *Access to Information in a Digital World* (Ottawa: Canadian Library Association, 2004) 109.
- <sup>9</sup> *Ibid.*
- <sup>10</sup> *Ibid.*
- <sup>11</sup> Even related unpublished work is rare: see P. Ross, “University Technology Transfer: Public Dissemination or Commercial Exploitation—A Statutory Perspective” (LL.M. major research paper, Osgoode Hall Law School, 2005) [unpublished], which highlighted a province-by-province disparity in universities’ statutory authority for exploitation of intellectual property and public dissemination of information. The document is available from Perry & Wilkinson.
- <sup>12</sup> Canada, Social Science and Humanities Research Council, “SSHRC Research Data Archiving Policy,” online: <[http://www.sshrc-crsh.gc.ca/site/apply-demande/policies-politiques/edata-donnees\\_electroniques-eng.aspx](http://www.sshrc-crsh.gc.ca/site/apply-demande/policies-politiques/edata-donnees_electroniques-eng.aspx)> [SSHRC Data Archiving].
- <sup>13</sup> C.M. Perry, “Archiving of Publicly Funded Research Data: A Survey of Canadian Researchers” (2008) 25, *Government Information Quarterly* 133-48. Perry was a student in the M.L.I.S. program at The University of Western Ontario where her research was conducted under the supervision of

Margaret Ann Wilkinson. Because Perry's article is the original authority on this topic, we completed a search to identify publications that cited Perry's article, which allowed us to conclude that Perry's article remains the authority in the area. A search of the following databases—Heinonline, WestlawCanada, Quicklaw, Science Direct, Web of Science, Web of Knowledge, Scholars Portal, LegalTrac, Legal Scholarship Network (+ Cite Reader), CPI.Q, AcademicOneFile, and JSTOR—reported that Perry's article has not been cited.

- <sup>14</sup> The SSHRC has introduced the SSHRC Data Archiving Policy, online: <[http://www.sshrc.ca/funding-financement/policies-politiques/edata-donnees\\_electroniques-eng.aspx](http://www.sshrc.ca/funding-financement/policies-politiques/edata-donnees_electroniques-eng.aspx)>, which requires that research data collected while using SSHRC funding be archived for later use by other researchers. This policy was enacted solely by SSHRC; no corresponding policy exists from CIHR, the NSERC, or the *Tri-Council Policy Statement*. SSHRC data archiving requires all research data collected while conducting research funded by SSHRC to be archived within two years of completing the research project. SSHRC defines "research data" to include "quantitative social, political and economic data sets; qualitative information in digital format; experimental research data; still and moving image and sound databases; and other digital objects used for analytical purposes." SSHRC data archiving addresses the fact that the act of archiving research data may result in issues regarding the protection of the research subject's confidentiality. The policy states that although identifying information may be removed from the data set to protect confidential information, such action may render the data sets useless and, if this is the case, the researcher is to obtain advice on the appropriate action from the university's research ethics board.
- <sup>15</sup> Perry, *supra* note 13 at 145.
- <sup>16</sup> *Ibid.* at 146.
- <sup>17</sup> Canada, Canadian Institutes of Health Research, *CIHR Best Practices for Protecting Privacy in Health Research* (Ottawa: Public Works and Government Services Canada, 2005) [*CIHR Best Practices*].
- <sup>18</sup> *CIHR Best Practices, ibid.*, is independent of the *Tri-Council Policy Statement* and acknowledges that the law differs among provinces and territories and internationally. With these guidelines, *CIHR Best Practices* provides a Compendium of relevant legislation covering all provinces and territories, which outlines the effects of all legislation enforced on various aspects of health research. This is an excellent resource for researchers within any given province on how to proceed according to the laws within their jurisdiction. University researchers, however, are not given any indication whether the legislation outlined in the Compendium has been adopted in the ethics policies established by their university's research ethics boards. Best practices are a useful and important element of protecting a health-care practitioner and health institution from liability arising from certain health-related laws. They can, for example, serve as a defence to allegations of professional misconduct and negligence, because showing that a minimum standard of care was met is a good defence in such situations. However, the new reality is that, in the information age, it is the laws themselves that determine the outcome of disputes, irrespective of the judgment of the defendant. Therefore, the benefits of best practices with respect to the protection of personal information are not as great as they are for more traditional health-related disputes. University researchers will have little to gain from following these CIHR Best Practices and should instead follow applicable provincial and federal legislation more closely.
- <sup>19</sup> Two recent articles that fit within this stream of thought are E. Whittaker, "Adjudicating Entitlements: The 19 Discourses of Research Ethics Boards" (2005), 9 *Health* 513-35 and M. Aita & M.-C. Richer, "Illuminating the Process of Knowledge Transfer in Nursing" (2007), 4 *Worldviews on Evidence-Based Nursing* 146-55.
- <sup>20</sup> Recent articles that fit within this stream of thought include B.M. Knoppers, "Consent Revisited: Points to Consider" (2005), 13 *Health L. Rev.* 33-38; K.M. Weisbaum, P.M. Slaughter & P.K. Collins, "A Voluntary Privacy Standard for Health Services and Policy Research: Legal, Ethical and Social Policy Issues in the Canadian Context" (2005) 14 *Health L. Rev.* 42-46; D.J. Jones, "Interface of Law & Ethics in Canadian Research Ethics Standards: An Advisory Opinion on

- Confidentiality, Its Limits, & Duties to Others,” (2007) 1 McGill H.L.P. 101-115; D. Willison, “Privacy and the Secondary Use of Data for Health Research: Experience in Canada and Suggested Directions Forward” (2003) 8 J. Health Services Research & Policy 17-23; M. Hirtle, “The Governance of Research Involving Human Participants in Canada” (2003) 11 Health L.J. 137-52; P. Kosseim, “The Landscape of Rules Governing Access to Personal Information for Health Research: A View from Afar” (2003) 11 Health L.J. 199-216; and D.J. Willison, “Trends in Collection, Use and Disclosure of Personal Information in Contemporary Health Research: Challenges for Research Governance” (2005) 13 Health L. Rev. 107-13.
- <sup>21</sup> See S. Perrin *et al.*, *The Personal Information Protection and Electronic Documents Act: An Annotated Guide* (Toronto: Irwin Law, 2001) at 107, where, in commenting on the then new *Personal Information Protection and Electronic Documents Act* (PIPEDA), *infra* note 22, the authors state that the awarding of damages to the complainant by the Federal Court in PIPEDA “has specifically expanded the power of the Court”—that is, beyond the powers the Federal Court has in relation to the earlier public sector *Privacy Act*, R.S.C. 1985, c. P-21.
- <sup>22</sup> *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5 [PIPEDA].
- <sup>23</sup> See PIPEDA, *ibid.*, s. 16(c).
- <sup>24</sup> As well as all private sector organizations engaged in activities falling under federal jurisdiction.
- <sup>25</sup> *An Act Respecting the Protection of Personal Information in the Private Sector*, R.S.Q., c. P-39.1.
- <sup>26</sup> *Personal Information Protection Act*, S.A. 2003, c. P-6.5.
- <sup>27</sup> *Personal Information Protection Act*, S.B.C. 2003, c. 63.
- <sup>28</sup> *Canada Gazette*, “Alberta’s *Personal Information Protection Act* deemed substantially similar” (October 12, 2004); “British Columbia’s *Personal Information Protection Act* deemed substantially similar” (October 12 2004); “Quebec’s *An Act Respecting the Protection of Personal Information in the Private Sector* deemed substantially similar” (December 11, 2003); online: Officer of the Privacy Commissioner of Canada <[http://www.privcom.gc.ca/legislation/ss\\_index\\_e.asp](http://www.privcom.gc.ca/legislation/ss_index_e.asp)>.
- <sup>29</sup> PIPEDA, *supra* note 22, s. 2(1).
- <sup>30</sup> See Ross, *supra* note 11, who notes that Alberta’s universities are the exception because they have been statutorily declared to be public.
- <sup>31</sup> Among universities, the Royal Military College of Canada (RMC) is an anomaly when it comes to personal data protection. RMC is not listed in the schedule of either the federal *Privacy Act*, *supra* note 21, nor by relevant Ontario legislation (*Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F.31 (Ontario FIPPA) or its Regulations (R.R.O. 1990, Reg. 1015), despite the fact the school does have an Ontario Charter (*Royal Military College of Canada Degrees Act, 1959*).
- <sup>32</sup> *Access to Information and Protection of Privacy Act*, S.N.W.T. 1994, c. 20, as amended by S. Nu. 2003, c. 31, s. 2 (Nunavut).
- <sup>33</sup> *Access to Information and Protection of Privacy Regulations*, N.W.T., Reg. 206-96, s. 28 (Nunavut Regulations).
- <sup>34</sup> Nunavut, *supra* note 32.
- <sup>35</sup> Nunavut Regulations, *supra* note 33, Schedule.
- <sup>36</sup> *Access to Information and Protection of Privacy Act*, R.S.Y. 2002, c. 1 (Yukon).
- <sup>37</sup> See *Protection of Personal Information Act*, C.S.N.B. 1998, c. P-19.1 (New Brunswick); *Freedom of Information and Protection of Privacy Act*, R.S.P.E.I. 1998, c. F-15.01 (Prince Edward Island); and Yukon, *supra* note 36.
- <sup>38</sup> *Freedom of Information and Protection of Privacy Act* (FIPPA (Saskatchewan)), S.C. 2009, c. F-22.01 [FIPPA (Saskatchewan)].
- <sup>39</sup> *Local Authority Freedom of Information and Protection of Privacy Act* (LAFIPPA), S.C. 2006, c. L-27.1 [LAFIPPA].
- <sup>40</sup> FIPPA (Saskatchewan), *supra* note 38, s. 3(1).

- <sup>41</sup> LAFIPPA, *supra* note 39, s. 3(1).
- <sup>42</sup> *Ibid.*, s. 28(1).
- <sup>43</sup> *Ibid.*, s. 28(2)(k).
- <sup>44</sup> Ontario FIPPA, *supra* note 31.
- <sup>45</sup> *Municipal Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. M.56.
- <sup>46</sup> Ontario FIPPA, *supra* note 31, s. 65(8.1).
- <sup>47</sup> The following sections generally state that the Act does not apply to a record containing teaching materials or research information of an employee of a post-secondary educational institution: *Freedom of Information and Protection of Privacy Act*, R.S.A. 2000, c. F-25, s. 4(1)(i) (FOIIP (Alberta)); *Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c. 165, s. 3(1)(e) (FIPPA (British Columbia)); *Freedom of Information and Protection of Privacy Act*, S.M. 1997, c. 50, s. 4(g) (FIPPA (Manitoba)); *Access to Information and Protection of Privacy Act*, R.S.N.L. 2002, c. A-1.1, s. 5(1)(h) (ATIPPA (Newfoundland & Labrador)).
- <sup>48</sup> *An act respecting access to documents held by public bodies and the protection of personal information*, R.S.Q. 2005, c. A-2.1, s. 78.
- <sup>49</sup> When Nunavut was created (April 1, 1999), if legislation had yet to be created on an issue, the territory adopted legislation previously enacted by the Northwest Territories; this was the case for personal data protection legislation.
- <sup>50</sup> *McInerney v. Macdonald*, [1992] 2 S.C.R. 138, S.C.J. No. 57, aff'g 66 D.L.R. (4th) 736, 103 N.B.R. (2d) and 259 A.P.R. 423 (C.A.).
- <sup>51</sup> *Ibid.* at para 31.
- <sup>52</sup> These principles include facilitating the disclosure of personal medical information to patients.
- <sup>53</sup> See, in this connection, W. Peekhaus, "Personal Medical Information: Privacy or Personal Data Protection?" (2006) 5:2 C.J.L.T. 87.
- <sup>54</sup> In Ontario, the *Personal Health Information Protection Act* (PHIPA), *infra* note 55, s. 65 allows individuals to bring an action in front of the Ontario Superior Court of Justice for harm "suffered as a result of a contravention of this Act or regulations." The harmed individual may be awarded up to \$10,000 in damages. In Saskatchewan, the *Health Information Protection Act* (HIPA), *infra* note 57, s. 51 allows an individual to bring an action in front of a court for contravention of this act by a trustee. Upon hearing the action, the court has the ability to make any order that it considers appropriate (s. 51(5)). In Alberta, the *Health Information Act* (HIA), *infra* note 56 s. 82(4) allows an individual to make an application to the Court of Queen's Bench for a contravention of the Act. The Act does not specify the type of awards the court may grant an injured plaintiff. In Manitoba, the *Personal Health Information Act* (PHIA), *infra* note 58, ss. 49-55 allows appeals to a court only in relation to access to personal information requests. Under s. 56, without leave to appeal granted from the Manitoba Court of Appeal, decisions made under s. 55 are final and cannot be appealed.
- <sup>55</sup> *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3 (PHIPA). *Canada Gazette*, Ontario's deemed substantially similar to Part 1 of the Personal Information Protection and Electronic Documents Act, November 28, 2005, online: <[http://www.privcom.gc.ca/legislation/ss\\_index\\_e.asp](http://www.privcom.gc.ca/legislation/ss_index_e.asp)>.
- <sup>56</sup> *Health Information Act*, R.S.A. 2000, c. H-5 (HIA).
- <sup>57</sup> *Health Information Protection Act*, S.S. 1999, c. H-0.021 (HIPA).
- <sup>58</sup> *Personal Health Information Act*, C.C.S.M. 2005, c. P33.5 (PHIA).
- <sup>59</sup> From this perspective, it is irrelevant whether or not the provincial personal health data protection statutes in question have been deemed equivalent to PIPEDA by the federal government. It may also be useful to recall that Quebec has already exempted "scientific" research in universities from the purview of its personal data protection legislation, which may be taken to include considerable swaths of health research. (Quebec has no special sectoral health personal data protection legislation.)

- <sup>60</sup> LAFIPPA, *supra* note 39, s. 23(1.1)
- <sup>61</sup> *Ibid.*, ss. 2(f)(ix), (x), (xi), (xii).
- <sup>62</sup> PHIA, *supra* note 58.
- <sup>63</sup> The federal *Privacy Act*, *supra* note 21, protects personal information held by the governed public sector organizations for 20 years following death (s. 3(m) “personal information”) whereas, under PIPEDA, it protects an individual’s information held by private sector organizations either until 20 years after death or until 100 years after the document was created, whichever is less (ss. 7(3)(h)(i), (ii)). B.C.’s legislation also operates with a 20-years-after-death time frame (*Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c. 165, s. 22(4) taken together with s. 36(c)) and Nova Scotia’s legislation is similar (*Freedom of Information and Protection of Privacy Act*, R.S.N.S. 1993, c. 5, s. 20(4) taken together with s. 30(c)). Newfoundland’s legislation operates to protect information for 20 years after a person’s death or for 50 years after the document was created, at least where the information is held in archives (Newfoundland & Labrador, *supra* note 47, ss. 42(c) and (d)). Alberta and Saskatchewan protect personal information until 25 years after the individual’s death (FOIPP (Alberta), *supra* note 47, s. 17(2)(i), LAFIPPA, s. 29(1), and FIPPA (Saskatchewan), s. 30(1)). Prince Edward Island’s legislation generally protects personal information for 25 years after death (Prince Edward Island, *supra* note 37, s. 15(2)(i)). Ontario protects personal information until 30 years after death (Ontario FIPPA, *supra* note 31, s. 2(2); *Municipal Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. M.56, s. 2(2)) and Quebec does the same, unless the record is over 100 years old (*An Act respecting the protection of personal information in the private sector*, *supra* note 82, s. 18.2.). Manitoba, on the other hand, protects information only until 10 years after an individual’s death (the *Freedom of Information and Protection of Privacy Act*, C.C.S.M. 1997, c. F175, s. 17(4)). New Brunswick’s legislation contains no term of protection but appears to leave the matter open to regulation (*Protection of Personal Information Act*, C.S.N.B. 1998, c. P-19.1, s. 7).
- <sup>64</sup> *Tri-Council Policy Statement*, *supra* note 7 at i.3.
- <sup>65</sup> *Ibid.* at i.5.
- <sup>66</sup> *Ibid.* at i.8.
- <sup>67</sup> *Ibid.*, art. 5.1, which states that two members must have expertise in the fields of research examined by the board; one member must be knowledgeable in ethics; for biomedical research, one must be familiar with relevant law; and at least one must be a member of the general community without affiliation with the institution.
- <sup>68</sup> *Ibid.*, arts. 1.1, 1.6, 1.9.
- <sup>69</sup> *Ibid.*, art. 2.1.
- <sup>70</sup> *Ibid.*, art. 3.1.
- <sup>71</sup> *Ibid.*
- <sup>72</sup> As has been pointed out elsewhere, it would be difficult for the three councils to point to any such authority. See, for example, “Confidential Information,” *supra* note 4.
- <sup>73</sup> *Tri-Council Policy Statement*, *supra* note 7 at 31.
- <sup>74</sup> *Ibid.* at 3.2.
- <sup>75</sup> *Ibid.*, art. 3.2.
- <sup>76</sup> *Ibid.*, art. 3.4.
- <sup>77</sup> *Ibid.*
- <sup>78</sup> *Ibid.*
- <sup>79</sup> SSHRC, *supra* note 2, defines “post-secondary institution” as “a public or private not-for-profit degree or diploma-level university, university college or college established in accordance with appropriate provincial or territorial legislation” (see <<http://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/definitions-eng.aspx#a20>>).

- <sup>80</sup> Although this study is based on data obtained from 2006, the information this article is based on is still accurate as of 2010. For instance, the only provinces without coverage of universities in their access legislation are still Prince Edward Island and New Brunswick. All other provinces have coverage of universities in at least one access statute including Alberta (FOIPP Act), British Columbia (FIPPA), Manitoba (FIPPA), Newfoundland & Labrador (ATIPPA), Nova Scotia (FIOPOP), Ontario (FIPPA), and Quebec (*An act respecting access to documents held by public bodies and the protection of personal information*).
- <sup>81</sup> T. Keller, ed., *Maclean's Guide to Canadian Universities 2006* (Toronto: Rogers Publishing, 2006).
- <sup>82</sup> In analyzing the ethics policies of the 54 universities, we found that *all* of them specifically referred to the *Tri-Council Policy Statement*.
- <sup>83</sup> The research done by Perry, *supra* note 13, supports the inference that researchers will not independently analyze the law applicable to their circumstances and will instead rely completely on the rulings of their institution's research ethics board as certifying that their research is legally and ethically unassailable.
- <sup>84</sup> Discussion of access is outside the scope of this paper, but requirements that exceed the minimums of protection regimes will impede such access.
- <sup>85</sup> However, under the Ontario FIPPA, *supra* note 31, s. 69, an "institution" is defined in s. 2 to include various public sector bodies in Ontario.
- <sup>86</sup> The drafts and information on the reworked policies are online: Panel on Research Ethics <<http://pre.ethics.gc.ca/eng/policy-politique/initiatives/revise-reviser/Default/>>.
- <sup>87</sup> *Ibid.*, "Highlights of Changes" link.
- <sup>88</sup> And Nunavut and the Northwest Territories when universities develop.
- <sup>89</sup> And the Yukon, when universities develop.
- <sup>90</sup> The problems with such conflicts must be seen in light of the federal funding of university research. The federal government is the single largest contributor to direct costs of university research in Canada, at over three Billion, see <[http://www.aucc.ca/policy/quick-facts\\_e.html](http://www.aucc.ca/policy/quick-facts_e.html)>. Higher education ranks second (after the business sector) for research performance, at \$10.4 billion and contributes over one-third of total R&D in 2009, see <<http://www.statcan.gc.ca/pub/88-221-x/2009001/aftertoc-aprestdm1-eng.htm>>. Naturally, even provincially funded research tends to be of a collaborative nature that will go beyond provincial borders.