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Personal Health Information in Canada: Clearing the Conceptual Underbrush and Accounting for Public Opinion

Abstract: This paper explores the relationship between individuals and their medical information in Canada. It employs Neill's theoretical model of privacy to situate Canadian legislation, and also analyzes public opinion data about attitudes toward medical and genetic privacy, indicating areas where legislation and public opinion are out of synch.

Résumé: Cet article examine la relation qui existe entre les individus et leurs renseignements médicaux au Canada. Le modèle théorique de Neill sur la confidentialité est utilisé pour situer la loi canadienne. Cet article analyse également les données tirées de l'opinion publique concernant les attitudes envers la confidentialité médicale et génétique et souligne des points où la loi et l'opinion publique ne sont pas synchronisées.

1 Introduction

> All that may come to my knowledge in the exercise of my profession or outside my profession or in daily commerce with men, which ought not to be spread abroad, I will keep secret and will never reveal.
>
> - Hippocratic Oath, circa 4th century B.C.

The Hippocratic Oath, which at some level is probably familiar to a large portion of the population, actually articulates a tension in contemporary society between the call for privacy rights and claims that access to medical data is necessary for the benefit of all of society. The former is a position espoused by libertarians and the latter is championed by communitarians. The libertarian applauds the Oath's insistence that the medical practitioner keep secrets; the communitarian supports the notion, present in the Oath, that there is information that ought to be spread about. This tension mirrors the inevitable discordance between privacy (understood in the context of the Oath as secrets relating to an individual) and access (to the information that ought to be spread abroad).

Some of the existing literature concerning the privacy of health information seems to suggest that medical information has a particularly special nature; either through its oft-cited association with dignity or the need for its 'unobstructed' use by health care practitioners for a variety of reasons. It is against such a backdrop that this paper will examine the extent of privacy protection individuals enjoy over their medical information in Canada as a result of relevant federal and provincial legislation. Having established in the literature a lack of definitional and conceptual clarity, an attempt will be made to situate the Canadian legal environment in respect of privacy legislation within a suitable theoretical framework: Elizabeth Neill's (2001) model of privacy. The paper will also discuss a statistical analysis of survey data about attitudes toward the protection of medical information, with an emphasis on genetic privacy, in order to demonstrate areas of convergence and divergence between legislative protection and actual public opinion in Canada. Part of this discussion will also be directed toward those areas of public opinion that do and do not accord with Neill's model. The research questions driving this paper include the following four:

i) What protections for personal medical information do the federal *Personal Information and Protection of Electronic Documents Act* and the four provincial (Alberta, Saskatchewan, Manitoba, and Ontario) health information protection acts provide Canadians?

ii) Does the theoretical literature on privacy offer a convincing model that can underwrite an analysis of Canadian personal health information protections?

iii) Do the various provincial health information protection acts go beyond the *Personal Information and Protection of Electronic Documents Act* such that health information protection might better be considered more about privacy than personal data protection?

iv) Do the privacy protections for genetic information that are established in Canadian legislation accord with public opinion about how this type of medical information should be treated?

In order to respond to these questions, the first part of the paper will engage in a comparative examination of the Canadian federal *Personal Information and Protection of Electronic Documents Act* and the four provincial (Alberta, Saskatchewan, Manitoba, and Ontario) health information protection acts. The following section will consider some of the dominant theoretical conceptions of privacy prevalent in the literature, with attention focussing on an explication of Neill's ontology of privacy. Attention will then turn toward an assessment of whether the various statutes are concerned more with privacy or personal data protection, and where they fit in the privacy debate based on Neill's model. The final section of the paper will broaden the preceding description and interrogation by offering empirical examples of public opinion in respect of medical and genetic privacy.

2 Legislative Protections of Personal Health Information

Although the notion of privacy is not a modern concept[1], it has only been within the last three decades that privacy legislation has actually been drafted in much of the developed world. For the most part, the national privacy legislation of the 1970s and 1980s was generally designed to address concerns about the privacy relationship between the individual and the state.[2] Yet, in the interim, transformations in the economic, political, and technological landscape have occasioned the locus of concern regarding privacy protection to shift toward a sharpened emphasis on the commercial exploitation of personal information (Agre and Rotenberg 1997; Bennett and Grant 1999; Laudon 1996). The health sector has been caught up in these changes and has not escaped domestic and international pressures for minimum standards of protection for personal information, as well as harmonization between jurisdictions.

2.1 Federal Protection of Personal Information

Although in Canada personal information maintained by the federal government was first safeguarded by Part IV of the *Human Rights Act* of 1977 and subsequently through the *Privacy Act* of 1982, which came into force on July 1, 1983, it was not until April 13, 2000 when the *Personal Information Protection and Electronic Documents Act* (PIPEDA) received Royal Assent that federal protection began to be extended to information held by the private sector in Canada.[3] In the meantime, protection of personal information throughout much of the rest of the public sector in Canada had gradually been enacted.[4] Part of the motivation behind enacting the PIPEDA for private sector privacy protection was international pressure from the European Union, the member states of which, in adherence to its Data Protection Directive, limit transnational data flows to only those foreign countries with similar legislative mechanisms in place. As the legislative history of the PIPEDA points out, "Part I of Bill C-6 (PIPEDA) also responds to recent privacy initiatives in Europe. … The Directive [EU Data Protection Directive] could, therefore, have a negative impact on Canadian businesses engaged in commerce with companies in European Union countries, unless adequate privacy legislation is introduced in Canada" (Craig 1999). In a decision from December 20, 2001 the EU Commission stated that Canada's PIPEDA did meet the required standard under its Data Protection Directive (European Commission 2001). Thus, the PIPEDA achieved the objective of ensuring that European Union Member State companies could continue to do business with Canadian firms.

The PIPEDA came into full force on January 1, 2004: the Act now covers all information collected, used or disclosed during the course of commercial activities by private sector organizations not governed under equivalent provincial legislation. It is the 'commercial clause'[5] that the federal government has used to constitutionally justify the reach of the PIPEDA into what otherwise might be considered provincial jurisdiction. The application of this notion of "commercial activity" to the health sector has caused much initial and unresolved confusion since health has traditionally been an area of provincial legislative activity.[6]

As defined by the PIPEDA, " 'commercial activity' means any particular transaction, act or conduct or any regular course of conduct that is of a commercial character, including the selling, bartering or leasing of

donor, membership or other fundraising lists" (*Personal information protection and electronic documents act* 2000, ss. 2(1)). Aside from being circular, such a definition does not go very far in helping to clarify the scope of the Act. As the Canadian Institutes of Health Research have pointed out:

> There are some important activities in the health sector, the nature of which cannot yet be clearly determined one way or another. For example, whether the services of a health professional carried out in a private clinic reimbursed by the public purse will be considered "commercial activity" within the meaning of the PIPED Act is not yet known. Whether the activities of private, not-for-profit organizations and/or cost-recovery activities constitute "commercial activity" is likewise impossible to ascertain at this stage and will likely be circumscribed over time through judicial interpretation (Canadian Institutes of Health Research 2001, p. 8).

There is an element of the PIPEDA itself, however, that might render these constitutional concerns largely redundant; namely the "substantially similar" clause, which exempts provinces from having to adhere to the Act if they pass legislation that the federal government recognizes as "substantially similar" to the PIPEDA.[7] If the four provincial health information protection acts examined in this paper are so recognized by the federal government, then not only would the PIPEDA no longer apply to health information within those provinces but such information would receive constitutionally unambiguous protection through provincial acts. As of writing, only Ontario's PHIPA has been recognized as being 'substantially similar' (Canadian Department of Industry 2005).[8] It should be pointed out that even if the provincial acts are deemed equivalent to the PIPEDA, it is the federal government's position that the federal act would still apply to a health care provider or hospital when engaging in inter-provincial and international commercial dealings (Canadian Department of Industry 2002, 2005).

The PIPEDA is an interesting piece of legislation in that it articulates the bulk of its requirements related to fair information practices in a Schedule rather than directly in the Act. Moreover, Schedule 1, which sets out the main information handling provisions with which all organizations subject to the Act must comply, is, verbatim, the *Model Code for the Protection of Personal Information* developed by the Canadian Standards Association (CSA Code) in 1996.[9] This Schedule very closely resembles the OECD Guidelines developed in 1980, which is not surprising given that Canada adopted them in 1984, and both the Schedule and the Guidelines are motivated by the desire to strike a balance between privacy and the free flow of information for commercial purposes.

The PIPEDA provides exemptions from coverage with respect to personal and domestic use of personal data as well as for journalistic, artistic, or literary purposes. Where these exemptions do not apply, the PIPEDA generally requires the knowledge and consent of the individual who is the subject of the data (data subject) before any personal information may be collected, used, and/or disclosed. There are, however, some important exceptions. Collection may occur without consent if consent cannot be obtained in a timely manner or if it would compromise the availability or accuracy of the information, or if the collection is necessary to investigate a crime.[10] Personal information can be used without consent for police investigations, in a case of an emergency that threatens the life, health, or security of an individual, and for statistical or scholarly study or research as long as confidentiality is ensured.[11] Disclosures of personal information may be made by an organization without the knowledge or consent of the data subject for debt collection, law enforcement, national security, emergency situations, statistical compilation and research[12], to comply with a subpoena or warrant, and at the earlier of either 100 years after the record was created or twenty years after the death of the individual to whom the information pertains.[13] Moreover, if these exemptions apply, an organization may disclose personal information for purposes other than those for which it was collected.

PIPEDA does not hamper the provinces from enacting legislation within their respective jurisdictions. It purports to provide a baseline for the protection of personal information in Canada. In fact the 'substantially similar' clause invites provinces to develop their own legislation applicable to their distinctive needs and requirements. As mentioned, to date, four provinces have promulgated information protection legislation specific to the healthcare industry.

2.2 Provincial Protection of Personal Health Information[14]

All of the provincial acts, as opposed to the PIPEDA, apply to health care providers regardless of whether they are engaged in commercial activities. Alberta's *Health Information Act* (HIA) received Royal Assent on December 8, 1999 and came into force on April 25, 2001. Saskatchewan passed the *Health Information Protection Act* (HIPA) on May 6, 1999, which was proclaimed in force on September 1, 2003. Manitoba's

Personal Health Information Act (PHIA) was passed on June 28, 1997 and came into force on December 11, 1997. Ontario passed its *Personal Health Information Protection Act* (PHIPA), which came into force on November 1, 2004. Each of the four acts outlines similar purposes, including the following: to protect the privacy of individuals with regard to their health information; to enable access to and sharing of health information in order to provide health services and manage the health system; to prescribe rules for the collection, use, and disclosure of personal health information; to provide individuals with rights of access to and correction of their medical records; to establish remedies for contravention of the acts; and, to provide for independent reviews of decisions made under the act.[15] All four provincial acts apply to identifiable personal health information[16], which includes information about both mental and physical health, including genetic information.[17] All of the acts further specify their scope by outlining who qualifies as a "trustee" (Saskatchewan and Manitoba)[18], "custodian" (Alberta)[19], or "health information custodian" (Ontario)[20]. These are the people and organizations required to abide by the provisions of the acts with regard to the collection, use, disclosure, retention, and disposition of personal health information. They include physicians, hospitals, pharmacists, district health boards, medical laboratories, special-care homes, mental health care facilities, and ambulance services, among others. Trustees and custodians are also responsible for ensuring the security, confidentiality, accuracy, and integrity of personal health information in their custody.[21]

All of the four acts contain detailed sections pertaining to the collection of personal health information. In most cases, the collection of non-identifying information is permissible. Identifiable information may only be collected if it is directly related to and necessary to carry out a purpose specified by the act, which is usually the provision of health services. The acts provide that information should always be collected directly from the individual to whom it pertains unless otherwise authorized by the individual, impossible in the circumstances, or would result in the collection of inaccurate information. In Alberta and Manitoba, a custodian is only required to take reasonable steps to inform the individual of the purpose for the collection and there are no provisions about consent[22], while in Saskatchewan and Ontario consent must be informed, although it may be express or implied and does not need to be in writing.[23] Although, at face value, Alberta and Manitoba would appear to offer less protection, presumably most individuals would consent to the collection of personal health information by their health care provider in order to facilitate the diagnosis and treatment services being offered. Since all the acts restrict the scope of collected information to that necessary for treatment purposes, a legitimate argument could be advanced that this aspect of medical privacy is adequately protected by current legislation.

As mentioned previously, all four of the provincial acts apply only to personally identifiable information.[24] In general, under these acts, personally identifiable health information may only be used to provide health services, for purposes consistent with those that gave rise to the original collection, to determine the eligibility of a patient to receive a health service, to monitor and prevent or reveal cases of fraudulent use of publicly funded health services, to conduct research (subject to ethics committee review), to conduct investigations relating to members of a health profession, to provide health services provider education, to obtain payment for services, to conduct internal management activities, to comply with subpoenas, warrants, or orders issued by a court, and for use by a prescribed professional body to discharge its duties.[25] Additionally, in Alberta, provincial health boards, regional health authorities and the Minister and Ministry of Health may use identifiable health information for planning and resource allocation, health system management, public health surveillance, and health policy development.[26] Similar provisions are also found in Saskatchewan's and Manitoba's legislation.[27] In Ontario, provisions related to planning and management of the health system are contained in the sections of the Act devoted to disclosure. The relatively broad range of institutions in all four provinces that can use personal health information without the consent of the information subject has occasioned at least one observer to claim that the provincial statutes "have been variously described as having very little to do with privacy and [are] much more concerned with providing government and researcher access to confidential medical records" (Fraser 2004, p. 5). While there is certainly some truth to this accusation, these exemptions are not surprising when one considers that all the statutes were enacted by provinces; provinces that are responsible for administering and substantially funding the healthcare systems within their jurisdictions. Without reliable information about those systems, management in times of tight fiscal conditions and rising expectations is made quite difficult, if not impossible.

All four of the provincial acts also contain provisions that require ethics approval for research using personally identifiable health information. Section 50 of Alberta's HIA empowers the ethics review board to determine whether consent is required from the individual to whom the information pertains. Similarly, Saskatchewan's HIPA allows for use of personal health information without consent if "in the opinion of the research ethics committee, the potential benefits of the research project clearly outweigh the potential

risk to the privacy of the subject individual" (*Health information protection act* 1999, paragraph 29(2)(c)). Manitoba's PHIA and Ontario's PHIPA contain very similar provisions.[28] The research exemptions in the provincial acts are roughly analogous to the scholarly research exemption contained in paragraph 7(2)(c) of the PIPEDA.

The four provincial acts contain disclosure provisions that generally prohibit health care providers from disclosing identifying health information without consent, unless permitted or required by another section of the respective act. In addition to release to other health practitioners and for research purposes, all of the acts permit disclosure without consent for evaluation purposes by quality of care committees, in court proceedings, for police investigations, for investigations by provincial Ministries of Health for fraud detection purposes, and to health professional regulatory bodies if required for investigations.

Having briefly considered the substantive elements contained in the federal PIPEDA and the four provincial acts relating to personal health information, the following section of the paper will review some of the dominant theoretical models of privacy found in the literature in order to situate the Canadian legal environment within an appropriate conceptual framework.

3 Theories of Privacy

The modern genesis of concerns over privacy is usually dated to the oft-cited article published in 1890 by the Americans Warren and Brandeis, in which they articulated privacy as "the right to be let alone" (Warren and Brandeis 1984, p. 75).[29] Despite this early treatment of privacy, it really was not until the 1960s that privacy emerged as an academic interest, in part tracing its roots to the seminal book by Alan Westin in 1967, *Privacy and Freedom.* The relative youth of this area of study is reflected by the panoply of heterogeneous definitions contained within the academic literature; many writers often lament the difficulty associated with developing an all-encompassing explication of the concept of privacy. In fact, in 1995 Alan Westin himself stated at a conference that "no definition of privacy is possible, because privacy issues are fundamentally matters of values, interests, and power" (Gellman 1997, p. 194).

Of course, some of the problem with developing a universal definition of privacy arises from the interdisciplinary nature of the debate. Law, sociology, philosophy, policy studies, and even some technological disciplines approach the study of privacy from different perspectives, so a lack of unanimity might be expected. Part of the difficulty in reaching agreement on a broadly acceptable definition of privacy also stems from the fact that while "we all acknowledge its value in the abstract, there are numerous grounds for puzzling over its significance, and for being suspicious of its value" (Schoeman 1984, p. 1). Nonetheless, no discussion and analysis of privacy can proceed without first achieving conceptual clarity. The intent of the remainder of this section of the paper is to review the main approaches to theorizing privacy and to propose a suitable conceptualization that will both help situate Canadian legislation and guide the analysis of public opinion offered in section 5.

In addition to endeavouring to define privacy, the literature, and in particular the philosophical literature, is also broadly concerned with establishing a link between privacy and morality or, conversely, with demonstrating that privacy as a concept is not of particular moral value. Although Warren and Brandeis never define privacy in their now famous article, they do link it to *the right to be left alone* and respect for a person's *inviolate personality*. On this basis, they argue that privacy warrants its own specific legal recognition and protection that reflects the modern moral parameters of social interaction.[30] In contradistinction, Prosser (1984), also arguing from an American perspective, but much later, considers privacy to be an amalgam of variegated interests already protected by legislation and thus not deserving of special protection. Indeed, as Schoeman (1984) asserts, part of the debate around privacy centres on whether privacy is a distinctive and coherent issue.

As Schoeman (1984) has pointed out, there are a number of theorists who argue that the disparate nature of privacy issues means not only that they are nominally connected at best, but also that privacy justifications must ultimately be premised on principles independent of any concern with privacy. From this perspective, he suggests that privacy theorists might be divided into those who adopt a reductive approach and those who do not. The former camp asserts that privacy can be reduced to an otherwise already existing right, which often turns out to be a property right (Prosser 1984; Thomson 1984). Reductionists tend to be sceptical about the value of privacy or to emphasize the negative impact individual privacy can have on broader society by shrouding asocial or antisocial behaviour (Schoeman 1984). Engaging in an economic analysis of personal information, Richard Posner argues that the desire to keep information private derives

from an interest individuals have in maintaining social or economic advantage when engaging in transactions with others (Posner 1984). Richard Wasserstrom suggests that privacy might engender hypocrisy and deception by allowing people to present themselves in a manner that deviates from their true nature (Wasserstrom 1984). In part, communitarian scholars such as Amitai Etzioni have focussed on this presumed antisocial attribute of privacy by which people misrepresent themselves or hide unsociable behaviour (Etzioni 1999). However, a number of theorists reject this as a reductionist and simple antithesis, instead positing that privacy is a necessary requirement for individuals to fulfill their public roles (Murphy 1984; Westin 1984). The theorists who do not view the right to privacy as being reducible to something else tend to adopt either an intrinsic or a functional approach (Schoeman, 1984). An intrinsic approach views privacy as something to be valued for its own sake. For example, Bloustein (1964) argues that privacy values reflect fundamental human values and therefore are distinctive. Building on the work of Warren and Brandeis, he asserts that 'inviolate personality' encompasses individual dignity, personal autonomy, and personal uniqueness. The respect for these values of human dignity helps ground and unify deference for privacy (Bloustein 1964). A functional approach, while not reducing privacy to something else, attempts to explain, in terms of the various functions that it fulfills, why people value privacy. Often times these scholars, including Ruth Gavison (1984), emphasize different norms or values made possible by privacy. She attributes positive functions to privacy, asserting that it promotes liberty, moral and intellectual integrity, important relationships, and the ideals of a free society (Gavison 1984). Privacy, according to Gavison (1984), facilitates social interaction, in situations where there is profound disagreement, by allowing people to tolerate opposing positions that they might otherwise not be able or willing to openly acknowledge. Privacy also affords an individual a type of intellectual refuge in which he might deliberate upon unpopular ideas that might otherwise attract social sanction.

Part of the difficulty with most of the preceding conceptualizations of privacy is that they fail to resolve the relationship between dignity and privacy, and seem merely to attribute a taken-for-granted status to dignity. This conceptual weakness forces one to look to another theorist who has advanced a theoretical model capable of coherently defending claims to privacy.

3.1 Elizabeth Neill's Ontology of Privacy

In *Rites of Privacy and the Privacy Trade* Elizabeth Neill (2001) sets herself the task of developing a theoretical basis for the justification of privacy in the context of our technologically advanced society. At the core of her theory is the question of the ontological status of human dignity in relation to privacy, which permits her to delimit the boundaries of legitimate privacy interests and rights. As she correctly points out, much of the literature has been unable to determine definitively whether human dignity is an inherent characteristic of humans or rather something that is conferred by society (Neill 2001). Indeed, without an unambiguous theoretical foundation many of the definitions of privacy that depend upon appeals to human dignity crumble like sandcastles with the rising tide. By considering the notion of the 'sacred self', which is posited to be that part of the self integral to personhood, Neill is able to move beyond this debate.

Neill construes human dignity not as being inborn but rather as a "rationally constructed metaphor for innate properties" (Neill 2001, p. 5). In developing her theory, Neill further distinguishes between factual and metaphorical 'innateness'; the former being something that is congenital whereas the latter is a construction that represents the former properties. To further refine this distinction, Neill differentiates between physical and psychological natural properties, with the former reflecting subsistence properties and the latter being comprised of an individual's private and autonomous nature that helps a person attain a minimal level of psychological security. Neill asserts that the production of thought reflects privacy and autonomy at their most elemental level. It is the privacy and autonomy of thought that embodies a person's perception of her innate privacy and autonomy. It is thus from factually innate properties that society then develops a conception of human beings as dignified. From this moral conception springs the creation and bestowal of rights. Morality therefore serves to rationally and metaphorically reconstruct factual reality. In order to avoid criticism that metaphor cannot ground entitlement, Neill appeals to the work of such scholars as Lawrence Kohlberg and Philip Wheelwright who has defended "the ontological status of radical metaphor … [as] a medium of fuller, riper knowing" (as cited in Neill, 2001, p. 7).

The dual ontological nature of Neill's theory, which postulates rights as being both originally created and bestowed by society, rejects natural rights theory that views rights as fixed objects given in nature that can be discovered and applied by humankind. Similar to Lockean rights theorists, Neill asserts that the development of rights is a gradual process by humans using rational means, although she does reject the claim that individuals contract to preserve natural rights. Instead, Neill posits that humans bestow rights upon one another as a means of metaphorically expressing the meaning of innate properties in their lives. By definition, she therefore also rejects the notion that humans are born with rights. Rather humans, by

virtue of birth, are provided with the capacity to construct rights. By conceiving the right to privacy as both innate and culturally bestowed, Neill's theoretical model is able to differentiate between circumstances in which privacy is a political, social, and individual necessity reflective of the human dignity in which it is grounded and those in which claims to privacy stretch beyond any legitimate connection to the dignity of the 'sacred self' (Neill 2001).

As opposed to a number of other authors who seek to ground privacy rights in human dignity but never convincingly make the connection, Neill's theory reaches further back and effectively unpacks the concept as a deliberate construction erected on innate facts, which thus supplies the moral origin of rights; value and meaning attach to innate psychological properties by imposing value and meaning on the moral metaphor that represents them. The result is an emergent perception of humans as dignified, which, once generalized to include the duties of all individuals to all others, facilitates the cultural bestowal of rights. Indeed, in Neill's theory, it is on the basis of the moral metaphor of humans as inherently dignified that privacy and autonomy rights are culturally bestowed. However, it is important to remember that privacy and autonomy rights bestowed by society safeguard the moral ideal of individual dignity rather than the innate properties of individual privacy and autonomy, which the metaphor of human dignity represents.

3.2 Applying the Model

While society safeguards the basic conception of human dignity through static norms,[31] individuals may attempt to have their entire persons viewed as sacred and therefore deserving of privacy protection. This, however, is a mistake, according to Neill, because it conflates the privacy of a private life with privacy of the 'sacred self' and attempts to extend the 'sacred self' beyond its inherent limits. Given this, Neill asserts that the criterion that should be applied when deciding whether an infringement of a privacy right is legitimate is the degree to which that right protects either the 'sacred self' or society's moral conception of the dignity of humans. Put another way, decisions about what constitutes a legitimate claim to privacy must be decided by the degree to which they are grounded in an individual's ideologically deep, or what she terms 'untradeable', right of privacy and human dignity. A 'true' privacy right would adhere to information *of* the body, which reflects the 'sacred self', unlike information *about* the body. Neill therefore believes that policy analysis and legislative development should be guided by concern for human dignity, and the ideologically deep privacy rights that attach to this, rather than broader privacy claims. As she argues, "the potential violation of innate dignity rights is the only viable reason for a privacy right" (Neill 2001, p. 135). In order to determine whether an interest merits protection, its origin must be traced back through Neill's structure of rights. Many norms, while making claims to privacy and autonomy rights, bear little relationship to symbolic or psychological properties and rights. As Neill asserts, many that fall within this category are often protective of economic interests masquerading as privacy concerns.

Although not explicit, Neill's distinction between the privacy of the 'sacred self' and the broader privacy rights associated with the 'rights trade' that can be exchanged for other goods appears roughly analogous to the differences between privacy and personal data protection.[32] With reference to Neill's ontology of privacy rights, the various provincial legislative devices in respect of medical information discussed in section 2.2 can be evaluated in terms of the degree to which they address either privacy claims or data protection imperatives. It is exactly such an analysis of the statutory protection for personal health information that will be taken up in the next section.

4 Health Information Protection: Privacy or Personal Data Protection?

Although an exhaustive discussion of all of the provisions contained within the four provincial acts is beyond the scope of this paper, the areas highlighted in section 2.2 do reflect the most substantive elements of each piece of legislation. While the PIPEDA does bestow the force of Canadian law upon 'fair information practices', it is argued here that the rights outlined by the Act are void of the moral legitimation integral to Neill's privacy model. They do not derive from absolute, static norms based on the innate natural properties of the 'sacred self'. Instead, the federal Act is strongly motivated by commercial imperatives. This is made most evident by the Act's reliance on the CSA Code, which closely resembles the OECD Guidelines in the latter's attempt to strike a balance between personal data protection and the free flow of information for business purposes. Similarly, the fact that the development and passage of the Act was in large part motivated by concerns about trade between Canada and the EU, as discussed in section 2.1, offers further evidence of the commercial elements driving the PIPEDA.

The PIPEDA is actually quite candid about its intended purpose and does not presume to safeguard privacy under the rubric of the 'sacred self'.[33] It is clear that the trade-offs in the legislation endeavour to satisfy

competing public policy goals in an attempt to ensure Canada continues to profit in the 'information economy'. Rather than appealing to a fundamental sense of privacy and the necessity of ensuring its protection, the Act specifies a purpose of balancing personal data protection against commercial interests. As such, the provisions of the federal Act revolve around what Neill would classify as broad rights to a private life and trade transgressions, and thus, more aptly, are considered protective of personal data rather than the privacy of the 'sacred self'. Clearly, the rights enumerated by the PIPEDA are not protective of Neill's conception of the 'sacred self', but neither do they make that claim. The attempt by the Act to legislate some level of data protection without couching it in terms of a fundamental appeal to the dignity of privacy is certainly in line with Neill's model.

Despite differences, the preceding review has also made it clear that a number of the obligations imposed by provincial statute mirror similar requirements found in the PIPEDA. Support for this position may be found in the fact that it has been argued, at least in Ontario, that "Most physicians who have developed privacy policies to comply with PIPEDA will only have to make minor adjustments to them as a result of PHIPA" (Steinecke 2004). Each piece of legislation attempts to vest in the individual some degree of control over personal health information by implementing consent requirements before others may collect, use or disclose personally identifiable information. Such consent requirements notwithstanding, beyond protecting the privacy of an individual's medical information, each of the statutes outlines the additional purpose of fostering an unimpeded exchange of information within an increasingly diverse healthcare system. Indeed, each provincial law, similar to the PIPEDA, contains multiple provisions that provide for use and disclosure of information without the consent of the information subject. A number of these provincial exemptions are motivated by other public policy concerns, such as permitting the exchange of information in order to facilitate medical treatment, allowing for the collection of data that can be used for performance evaluation of the healthcare system, facilitating research, and detecting fraud, among other things.

As discussed above, Neill asserts that only information *of* the body, which is considered to reflect the 'sacred self', deserves privacy protection. Yet, the medical information that is safeguarded by each of the provincial acts includes both mental and physical information and is therefore both *of* and *about* the body. According to Neill, however, only the mental health information, *of* the body, would warrant privacy protection based upon an appeal to the 'sacred self'. Again, it is important to recall that Neill does not argue against providing any protection for physical health information (*about* the body), rather she argues that the justification for any such safeguards must be made with reference to values other than privacy protection. Indeed, the multiple, and seemingly incongruous, policy goals of the four provincial health information protection acts appear to attempt to strike a balance between access and privacy, making it clear that protection of the 'sacred self' is not the overarching objective. Instead, each act appears to consider privacy in terms of its instrumental value. The various provisions of the statutes are premised on utilitarian concerns about maintaining the patient-healthcare provider relationship, advocating and offering autonomy to individuals over their own information, and perhaps preventing economic harm and humiliation of individual patients. The exemptions and limitations written into each piece of legislation, which actually reduce privacy protection, are ostensibly designed to benefit society by facilitating information flow within the healthcare system. Insofar as this concerns physical health information, these four provincial acts align with Neill's model. But the provincial health information protection acts fail to differentiate between mental and physical health information. Thus, the instrumental treatment of mental health information under the provincial acts fails to align with a position close to the 'sacred self' that Neill would afford this type of information in her model. Based upon the overall wording and effects of the provincial acts, it can be argued that health protection legislation in Canada finds a place at the fluctuating norms and protection of broad privacy rights level of Neill's ontology. While this allies with Neill's treatment of physical health information, the inclusion of mental health information at this level of protection is difficult to reconcile with her ontology of privacy rights.

The fact that there is a deliberate balance between privacy and access legislated into the provincial health information acts and the federal PIPEDA demonstrates that all are closer to personal data protection than to privacy. Indeed, it is quite telling that all of these statutes regulate how information may be collected, used, and disclosed, rather than whether such actions should be permitted in the first place (Wilkinson 2004). After all, if they were motivated exclusively by a desire to safeguard privacy, they would contain extremely limited access provisions based on explicit consent by the information subject. Put another way, if these statutes were concerned predominantly with privacy, they would privilege this goal to the near exclusion of access. However, to varying degrees, they all seek to strike a balance between the protection of personal information and access, which is, in fact, consistent with Neill's model. Indeed, although Neill does not explicitly employ the language of access, she does assert that personal information, including health

information, that is not protective of the 'sacred self' may legitimately be used for decision-making purposes. Thus, Neill's model helps to explain and make sense of the nature of contemporary medical information protection legislation, including the trade-offs contained within. The relative youth of these acts means that we currently lack convincing empirical evidence to determine whether the legislated balance goes too far in either direction. Proponents of increased access to medical information forecast improvements to the overall health of the community (Gostin 1995; Kulynych and Korn 2002; Tu et al. 2004; Upshur, Morin, and Goel 2001). Again, however, more rigorous investigation is necessary if we are to determine whether the benefits that purportedly accrue through greater access would offset the potential disadvantages that might adhere to the corresponding necessary reduction in autonomy and control over personal information.

It should be clear from the foregoing analysis and discussion of these federal and provincial enactments that the provincial acts go beyond the PIPEDA in protecting personal health information. Nonetheless, there are similarities between these federal and provincial laws, in terms of consent requirements and trade-offs between protection and access, which undoubtedly are motivated by desires to keep the broader economy and health sector functioning. For this reason, these statutes might better be considered more about personal data protection than about privacy. Having outlined and theoretically situated the main elements of the various statutory instruments designed to safeguard personal (health) information in Canada, the following section of this paper will examine public opinion in respect of medical and, in particular, genetic privacy.

5 Public Opinion about Issues of Medical and Genetic Privacy

5.1 Data Source and Methodology

This analysis is based upon the data from a survey concerning medical and genetic privacy that was commissioned by the Biotechnology Assistant Deputy Minister Coordinating Committee (BACC) of the Government of Canada.[34] Pollara Research and Earnscliffe Research and Communications, a leading public opinion and market research firm in Canada, completed the survey on behalf of BACC. The survey was conducted by telephone between February 10, 2003 and February 20, 2003 and included a random sample of 1224 Canadians from all ten provinces (at the time that this survey was conducted, only Alberta, Saskatchewan, and Manitoba had enacted health information protection legislation). The margin of error for the survey is 2.8%, 19 times out of 20. The survey instrument, which was developed through collaboration between Pollara Earnscliffe and members of the Privacy Working Group of the BACC, was pre-tested on 50 random respondents before the survey instrument was finalized. The objective of the survey was to establish a baseline of opinion about medical privacy, with an emphasis on genetic privacy issues, in order to provide evidence for federal policymakers in Ottawa (Pollara Earnscliffe 2003). Although the report issued by Pollara does not indicate whether any validity and reliability checks beyond random sampling and pre-testing were conducted, the expertise of the surveyors coupled with the presumed impartiality of the Government of Canada, which commissioned the survey, provide compelling evidence that the raw survey data are a quality source for the secondary statistical analysis conducted for purposes of this paper.

The majority of questions contained within the BACC survey elicited responses on an ordinal scale. Since it is impossible to compute standard descriptive statistics such as the mean and standard deviation for nominal or ordinal measurements, the statistical analysis conducted for this research project relied on non-parametric tests such as chi-square, Friedman, and the Spearman correlation.[35]

5.2 Discussion of the Findings

The survey demonstrated that while 60% of respondents are somewhat or extremely concerned about the way organizations handle and protect their medical information, this number drops to 47% for genetic information. Conversely, the percentages are higher, 75% and 61% respectively, for financial information and information about communication habits, such as use of the telephone or computer. A Friedman test demonstrated that the differences in level of concern about treatment between these four types of information are statistically significant, F_r (3, n = 1224) = 370.37, $p < .05$.

The differing responses to these questions about the way different types of information are handled by organizations were compared against the respondents' income, education, and province of residence. The latter variable, province of residence, was of particular interest given that only three provinces had enacted health specific data protection legislation at the time of this survey. A reasonable assumption might

suggest that people's concerns about medical and genetic information differ across provinces, with residents of provinces that have enacted health-sector specific legislation showing less concern about how their medical and genetic information is handled. However, chi-square tests comparing concerns about medical information handling and province [$?^2$ (48, n = 1224) = 49.35, p > .05] and concerns about genetic information handling and province [$?^2$ (48, n = 1224) = 59.93, p > .05] showed no significant difference by province.

The relatively low level of concern about how genetic information is handled might partly be explained by the fact that genetics is still an area of science not familiar to large parts of the population, although 60% of those surveyed claim to be either very familiar or somewhat familiar with issues involving genetic information. A chi-square test demonstrated that level of concern among respondents about the treatment of genetic information is, indeed, related to their familiarity with genetic issues: $?^2$ (16, n =1224) = 41.20, p < .05. In general, those respondents who are more concerned about the treatment of their genetic information tend to be more familiar with issues involving genetic information than those respondents who express less concern about how their genetic information is handled. A Spearman correlation determined a statistically significant relationship between these two variables: r_s = +.111, n = 1224, p < .05, two-tailed. This may well indicate that overall concern about the way genetic information is treated in Canada will rise in the future as more people become aware of the issues involved with genetic information.

As might be expected, given their reactions in the areas just discussed, a number of respondents believe that the laws and regulations pertaining to the treatment of communication habits information (31%) and financial information (39%) are very stringent or somewhat stringent. And, while about the same number (38%) believe that laws and regulations pertaining to genetic information are somewhat or very stringent, a much larger number (57%) of respondents hold the same views with respect to medical information laws and regulations. A Friedman test showed that the differences in attitudes about the stringency of laws in respect of these particular types of personal information (genetic, medical, financial, and communication habits) are statistically significant, F_r (3, n = 1224) = 276.95, p < .05. At first glance the lower number of respondents who think that the law concerning genetic information is stringent appears somewhat surprising given that more people are concerned about how medical information is handled than genetic information: one might intuitively expect that people think genetic information is more stringently regulated than medical information. However, 23% of respondents either answered "don't know" or did not respond to this question about genetic information, whereas only 8% of respondents either did not know or did not respond about the stringency of laws in respect of medical and financial information. The number of respondents who answered this way was 10% for the question about the stringency of laws and regulations pertaining to communication habits information. Taken together with the fact that a later question in the survey reveals that 85% of respondents are not familiar with current systems that regulate genetic information in Canada, it may be a fair inference that the non-response group in the genetic information laws question does not indicate complacency or satisfaction with the state of genetic information regulation, but rather an inability to judge.

Spearman correlations were calculated to determine whether there are statistically significant relationships between these views about the stringency of laws and the respondents' province of residence. Again, considering that only three provinces had enacted medical privacy legislation by the time the survey was conducted, a reasonable assumption might be that there is a relationship. This assumption was confirmed, although the correlations were not very strong: r_s = +.088, n = 1224, p < .05, two-tailed for attitudes about the stringency of laws regulating medical information and province of residence; r_s = +.080, n = 1224, p < .05, two-tailed for attitudes about the stringency of laws regulating genetic information and respondents' province of residence.

From the study, it can also be seen that people who have themselves undergone genetic testing tend to consider genetic information to be different from other medical information more often than is the case for those who have not undergone testing. 60% of individuals who have had a genetic test believe that genetic information is different from other medical information, as opposed to 53% in the overall sample. A chi-square test demonstrates that this finding is significant: $?^2$ (4, n =1224) = 60.64, p < .05. However, it should be pointed out that only 67 people (6%) in the sample of 1224 have actually undergone genetic testing.

The survey determined that 53% of respondents believe that genetic information is different from other types of health information such as medical history or family medical history, while 45% think it is the same. A chi-square goodness of fit test demonstrates that this difference is significant ($?^2$ (1, n = 1195) = 8.88, p < .05), although no statistically significant correlations were found between this variable and

variables such as the respondents' income, education, or province of residence. These results are opposed to Neill's model, which, as mentioned above, does not posit a distinction between genetic and health information. Nonetheless, the fact that 53% of respondents think that genetic information is different from other types of health information might suggest that future policy discussions about the protection of medical information may need to consider whether genetic information merits *sui generis* protection.

In fact, the survey indicated that 58% of respondents think that access to genetic information should be more strictly regulated than access to other health information, while 39% believe the rules governing access to genetic information should be regulated in the same way as other health information. A chi-square test showed that these are statistically significant differences: $?^2 (1, n = 1191) = 45.58, p < .05$. There is not, however, a statistically significant association between attitudes about how strictly to regulate access to genetic information and province of residence: $?^2 (24, n = 1224) = 33.79, p > .05$. Again, these findings could indicate that governments throughout Canada might need to consider developing and implementing specific regulatory schemes for genetic information.

A chi-square test of independence confirmed that attitudes about whether genetic information is different from other types of health information are not independent of attitudes about how strictly access to genetic information should be regulated as compared to other health information: $?^2 (4, n = 1224) = 89.96, p < .05$. In fact, a statistically significant Spearman correlation was also found between these two variables: $r_s = +.171, n = 1224, p < .05$, two-tailed. Those respondents who consider genetic information to be different from other health information were more likely to believe that access to the former type of information should be more strictly regulated than access to the latter type. Indeed, 66% of those respondents who think genetic information is different also believe that access to this information should be more strictly regulated, whereas only 49% of those participants who consider genetic information to be similar to other medical information think access to genetic information should be more strictly regulated. Again, these findings do not accord with the perspective evident in the provincial health information protection legislation, which considers genetic information to be a species of broader health information.[36] The relatively large numbers of respondents who think that genetic information is different from other health information and should be treated differently might indicate that policymakers need to revisit the issue of how genetic information should be regulated. Considered from the perspective of Neill's (2001) model of privacy, one might not expect such a relatively large number of respondents who believe that genetic information is different from other health information and who think that the former should be regulated more stringently than the latter. Neill, as discussed, considers both genetic information and other types of health information as similar, '*about* the body', interests, each representing a fluctuating right and interest rather than a static right protective of the 'sacred self' and thus a 'true' privacy interest.

Of those respondents who feel that access to genetic information should be more strictly regulated than access to other health information, 52% also believe that the medical and research community should play the main regulatory role, while 44% believe that the government should assume the main role ($?^2 (4, n = 1224) = 58.35, p < .05$. Although fewer people would mandate the government with the main regulatory role, the residuals from the chi-square test are negative for the medical and research community and positive for the government. Put another way, of the people who think that access to genetic information should be more closely regulated than other types of health information, significantly fewer people than expected want the medical and research community to have regulatory responsibility than is the case in the general population, and more people want government to assume the regulatory role. The reverse is true for people who would treat the regulation of genetic information no differently than that of other health information. Thus one might conclude that overall those people who think genetic information should be more strictly regulated than other health information tend to want government to assume the regulatory role, while those who do not believe genetic information should warrant stricter regulation tend to favour the medical and research community as the watchdog for the protection of genetic information.

The survey determined that 61% of Canadians believe a person has an obligation to inform family members of the results from a genetic test if there is something that could affect another family member. 37% do not think that an obligation arises. These differences were found to be statistically significant: $?^2 (1, n = 1197) = 68.81, p < .05$. This finding is interesting given that the legislation in place to protect medical information does not generally impose an obligation on individuals to share their genetic information with family members. This result also resonates with Neill's model, which, although it would not impose an obligation to disclose genetic information, certainly permits the disclosure of this type of personal information.

As mentioned previously, the survey findings indicate that 85% of respondents are either not very or not at all familiar with current systems that regulate genetic information in Canada. There is no statistically significant relationship between the respondents' familiarity with these regulatory mechanisms and their province of residence. This might indicate that the provinces with health sector specific legislation need to devote more attention toward educating their respective populations about the existence and nature of health information protection.

Survey participants were asked whether the benefits outweigh the drawbacks or the drawbacks outweigh the benefits if various people and organizations are permitted access to their genetic information. The people and organizations asked about included: doctors, pharmacists, nurses, medical researchers, governments, insurance companies, employers, and the person him- or herself. A Friedman test demonstrated that the differences across attitudes about allowing access to genetic information depending on the person or organization in question are significant: $F_r(7, n = 1224) = 3384.82$, $p < .05$. Chi-square tests for each person and organization, all of which were statistically significant using an adjusted alpha level of 0.0063, revealed large positive residuals; that is, there were more observed counts than expected counts of people who thought that the benefits outweigh the drawbacks of access in the case of doctors than of any other, followed by access by the subject of the data him- or herself, and then medical researchers, pharmacists, and nurses. On the other hand, more people who thought the drawbacks outweighed the benefits were found in the case of governments, followed by insurance companies and then employers, to whom the greatest perception of drawbacks attaches. These findings demonstrate that individuals' attitudes about the benefits of permitting access to their genetic information differ depending upon the person or organization seeking that access. In general, individuals believe that the benefits outweigh the drawbacks in allowing access to genetic information to the actors traditionally involved in healthcare delivery. Conversely, people are sceptical of the benefits of allowing employers, insurance companies, and governments access to their genetic information. Overall, these findings tend to accord with the purposes of the four provincial health information protection acts, which seek to facilitate the flow of information within the healthcare sector but limit its collection, use, and dissemination beyond the medical environment. A point of contention does arise with respect to government access, since all of the acts provide exceptions for provincial and federal government access to personal health information. Most of these allowances for government access are designed to facilitate the administration of the healthcare system, detect fraud, and respond to warrants and subpoenas and thus do limit government access. The wording of the question carried a connotation of carte blanche access for government. It would be interesting to determine whether attitudes among respondents change if government access is limited, as it is in the four provincial acts. People's concerns in this survey about permitting employers and insurance companies to access genetic information parallel an ongoing debate found in the literature that will no doubt assume increased relevance if genetic testing becomes more widespread in employment and insurance situations in the future.[37]

In fact, survey participants were also queried about whether insurance companies should be allowed access to an applicant's genetic information. An overwhelming 90% of respondents think that insurance companies should not have this right (a result which, as might be expected, is statistically significant: $?^2(1, n = 622) = 418.17$, $p < .05$.). Even when asked to consider the possibility that insurance companies would be exposed to major financial risks or that premiums for all customers would increase if insurance companies could not obtain this information, 86% and 83% of respondents, respectively, would still prohibit insurance companies from accessing this information. Chi-square tests determined that these results are statistically significant: $?^2(1, n = 1073) = 619.04$, $p < .05$ for the possibility that insurance companies would be exposed to major financial risks and $?^2(1, n = 1064) = 545.72$, $p < .05$ when asked to consider the possibility that premiums would increase across the board if insurance companies were denied access to genetic information. Similar statistically significant results were found for the question about whether employers should have the right to ask applicants or current employees about their genetic information, with 90% of participants voicing opposition to such a right for employers. These concerns are reflected in the four provincial health information protection acts since neither employers nor insurance companies are included in the definition of health information 'custodian' or 'trustee'.

Respondents were also questioned about whether medical researchers and health care companies should have access to genetic information for research and development purposes if people gave their consent for this use of their information. 73% of respondents believe that scientific researchers should be permitted access, while 22% would prohibit access, despite an individual's consent. Among those 22% of respondents who would not allow access, even with consent, 66% would change their mind if their names were completely removed from the genetic information being used. In comparison, only 47% of respondents are willing to give health care companies access to genetic information. Of the 49% who

would not allow health care companies to access genetic information, 53% would change their mind and allow access if names were completely removed from the research database. In this survey, it was assumed that in these particular questions about access for research purposes that the individual's whose genetic information was being considered had given consent. It would be interesting in further research to establish whether Canadians' attitudes toward this type of access to genetic information would change where the subjects had not given consent. Presumably, those who would not allow the various parties (researchers, health care companies, and so on) access to their genetic information would rise. Since all four provincial health information protection acts, and the PIPEDA, provide exceptions for using personal health information without consent for research purposes, it may be presumed that these exceptions do not sit well with many in the population. Nonetheless, it appears indisputable, even from these data, that individuals are less willing to contribute their genetic information to private corporate entities engaged in medical research than to public sector scientific researchers.[38]

When asked whether government should focus on protecting the "privacy of personal information"[39], on supporting "research and development to improve health care and create jobs", or balancing the two, 42% of respondents indicated that a balance is most appropriate, 25% value privacy most highly, and 31% think promoting research and development should be the main focus of government (chi-square test: $?^2(2, n=1198) = 55.54, p < .05$). These results are independent of the respondents' province of residence: $?^2(36, n=1224) = 47.75, p > .05$. Similarly, no statistically significant correlation was found between these views about government roles and the respondents' income. Although the provincial health information acts do not speak to government attitudes toward supporting research and development *per se*, the PIPEDA review in section 2.1 of this paper does indicate a substantial federal emphasis on promoting commercial activity. In fact, in describing the context for medical research in Canada, the Leaders' Forum[40] has stated that "The advent of the new economic order is calling for a new and challenging public policy paradigm where social priorities such as health, education and skills development become the drivers of information-era growth and competitiveness, especially in terms of research and innovation" (Leaders' Forum Steering Committee, 2004, p. 6). The fact that this survey indicates that a larger number of Canadians support a balanced approach than favour either privacy protection or facilitating R&D would seem to reinforce the balance that appears to be embodied in the PIPEDA and reflected in the broader research and development goals of the Government of Canada. These empirical findings about the attitudes of Canadians also accord with Neill's model of privacy that considers the protection of personal health information in this context a fluctuating right that can be traded legitimately against other rights.

Perhaps surprisingly, given their attitudes about regulating access to information and limiting insurance companies' and employers' rights to information, the survey indicated that more people (56%) think that the medical and research community rather than the government (41%) should play the main role in regulating the privacy of genetic information in Canada. This difference is statistically significant: $?^2(1, n=1176) = 28.79, p < .05$.

Those who think that the government should balance its role between protecting privacy and supporting R&D are more likely to believe that the medical and research community should play the main role in regulating genetic privacy (63%). Those respondents who think that the government should focus mainly on R&D believe that the medical and research community should play the main role in regulating genetic privacy (58%). Those who believe that government should focus more on privacy than R&D tend to favour government responsibility for the regulation of genetic information (52%). These differences were found to be statistically significant: $?^2(6, n=1224) = 179.4, p < .05$.

6 Conclusion

This paper has sought to explore the relationship between individuals and their medical information in Canada. Elizabeth Neill's ontology of privacy rights provided the theoretical underpinnings to analyze and situate certain Canadian legislation currently involved in regulating this relationship. The explication of Neill's model demonstrated that she considers human dignity to be a metaphor that assumes a dual role; it reflects the innate natural properties of privacy and autonomy, and, based on these original, innate properties, it provides the moral justification for constructing societal norms protective of privacy. Though Neill does not couch her analysis of privacy in terms of access to information or personal data protection, her model anticipates the tension between these policy goals. Neil's model demonstrates that medical information, with the exception of mental health counselling notes, should be protected by conventional fluctuating norms and therefore subject to tradeoffs with other fluctuating rights. Put another way, personal health information might legitimately be construed as more about personal data protection than privacy and

therefore subject to some opposing access demands. The preceding analysis demonstrates that current Canadian legislation in this area exhibits this tension. While it is true that no other theorists advocate an absolute privacy right, Neill's model remains more convincing than those of others precisely because she provides a reasoned explication of the link between dignity and privacy rights. The analysis of recent survey data shows that Canadian public opinion supports some of the competing public policy claims that tend to impinge upon the strict protection of personal medical and genetic information. For instance, survey respondents tended to favour allowing access to their medical and genetic information by the actors traditionally associated with healthcare provision and were often willing to accept a balance between the protection of personal information and the promotion of medical research. Nonetheless, there was also a feeling among participants that genetic information should be more strictly regulated than other medical information, a finding that is not easily reconciled either with current legislation or Neill's model of privacy.

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Endnotes

[1] cf. Flaherty, D. (1972). *Privacy in colonial New England*. Charlottesville: University of Virginia Press, examines privacy practices among the Puritans in Colonial New England; Moore, B. (1984). *Privacy: Studies in social and cultural history*. Armonk, NY: M.E. Sharpe, Inc., considers the nature and meaning of privacy in a number of ancient societies; and Schoeman, F.D. (1992). *Privacy and social freedom.* New York: Cambridge University Press, looks at privacy practices in ancient Rome.

[2] Concerned about the effect that disparate national treatment of personal data could have on commerce, the Organization for Economic Co-operation and Development adopted and published in 1980 *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data* in an attempt to spur harmonization of national legislation. Nonetheless, it was not until the 1990s that Canada began to adopt legislation based on these Guidelines that applied beyond the public sector to include commercial enterprises.

[3] On July 1, 1983, the same day that the *Privacy Act* was proclaimed effective, Part IV of the *Human Rights Act* was repealed. The entire ambit of rights protected by the latter act was codified in the new *Privacy Act* and the *Access to Information Act*, which also came into force on July 1, 1983 (Pundit Chotalia 1998). It must be pointed out that Quebec adopted private sector personal data protection legislation in 1993, which became effective in 1994 (Comeau and Ouimet 1995).

[4] British Columbia passed its *Freedom of Information and Protection of Privacy Act* (R.S.B.C. 1996, c. 165) in 1992. Alberta passed the *Freedom of Information and Protection of Privacy Act* (S.A. 1994, c. F-18.5) in 1994, which was subsequently included in the Revised Statutes of Alberta in 2000 (R.S.A. 2000, c. F-25). Saskatchewan passed its own *Freedom of Information and Protection of Privacy Act* in 1990 (S.S. 1990-91, c. F-22.01). Manitoba assented to its *Freedom of Information and Protection of Privacy Act* in 1997 (C.C.S.M., c. F175), which replaced *The Freedom of Information Act* (S.M. 1985-86, c. 6). Ontario passed its *Freedom of Information and Protection of Privacy Act* in 1987 (R.S.O. 1990, c. F.31). Public sector privacy in Quebec is safeguarded by *An Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information* (R.S.Q., c. A-2.1), adopted in 1982. New Brunswick has enjoyed public sector privacy protection since 1998 when its *Protection of Personal Information Act* was passed (S.N.B. 1998, c. P-19.1). Prince Edward Island passed its *Freedom of Information and Protection of Privacy Act* in 2001 (S.P.E.I. 2001, c. 37). Nova Scotians are protected by their provincial *Freedom of*

Information and Protection of Privacy Act passed in 1993 (S.N.S. 1993, c. 5). With the exception of Part IV(Protection of Privacy), which has yet to be proclaimed, Newfoundland's *Access to Information and Protection of Privacy Act* went into force in January, 2005 (SNL2002, c. A-1.1). The Northwest Territories and Nunavut are protected by the *Access to Information and Protection of Privacy Act* passed in 1994 (S.N.W.T. 1994, c. 20) and which went into effect on December 31, 1996. Under section 76.05 of the *Nunavut Act*, Nunavut adopted the same act under its own jurisdiction as of April 1, 1999. The Yukon, in 1995, also passed an *Access to Information and Protection of Privacy Act* that was proclaimed on July 1, 1996.

[5] ss. 91(2) of the *Constitution Act 1867*, which confers responsibility for inter-provincial trade and commerce upon the federal government, is often referred to as the so-called 'commercial clause'.

[6] The province of Quebec initiated a constitutional challenge against the PIPEDA on December 17, 2003. Although, as of writing, the Quebec Court of Appeal had not yet issued a ruling, it seems reasonable to assume that, given the nature of this challenge, it will make its way up to the Supreme Court of Canada.

[7] PIPEDA para. 26(2)(b) states that "The Governor in Council may, by order, if satisfied that legislation of a province that is substantially similar to this Part [1-Protection of Personal Information in the Private Sector] applies to an organization, a class of organizations, an activity or a class of activities, exempt the organization, activity or class from the application of this Part in respect of the collection, use or disclosure of personal information that occurs within that province."

[8] Although Alberta's *Health Information Act* has not been recognized as being 'substantially similar', the province's broader *Personal Information Protection Act* has been deemed equivalent to the PIPEDA so the health care sector must abide by this latter act until the former is recognized as being 'substantially similar'.

[9] The ten information principles set out in the CSA Code and Schedule 1 of the PIPEDA include: accountability; the need to identify collection purposes; consent; limitations on collection; limits on use, disclosure, and retention; accuracy; security safeguards; openness; individual access; and mechanisms to launch compliance concerns.

[10] PIPEDA ss. 7(1).

[11] *Id*. at ss. 7(2).

[12] The exemptions for use and disclosure of information without consent for statistical, or scholarly study or research also require that the information can only be used or disclosed if the purposes cannot otherwise be achieved, that it is impracticable to obtain consent, and that the organization informs the Privacy Commissioner before using or disclosing the information. The notification requirement notwithstanding, the Privacy Commissioner has no power to prevent use or disclosure.

[13] PIPEDA ss. 7(3).

[14] There are sections in various public sector privacy acts and public health acts that also govern certain aspects of health information in Canada. However, any treatment of these legislative devices is beyond the scope of this paper.

[15] HIA s. 2; HIPA contained in preamble to the Act; PHIA s. 2; PHIPA s. 1.

[16] In Alberta's statute "non-identifying" information is defined in paragraph 1(1)(r) as health information from which "the identity of the individual who is the subject of the information cannot be readily ascertained from the information". This type of information can generally be collected, used, and disclosed without restrictions as the majority of the Act applies to "individually identifying" information. The other provincial statutes actually define personal health information and although the definition set forth in paragraph 2(m) of Saskatchewan's HIPA is fairly broad, paragraph 3(2)(a) limits the scope of the Act so that it does **not** apply to "statistical information or de-identified personal health information that cannot reasonably be expected, either by itself or when combined with other information available to the person who receives it, to enable the subject individuals to be identified". Subsection 1(1) of Manitoba's PHIA defines "personal health information" as "information about an identifiable individual…" and section 3 of the Act states that "This Act does not apply to anonymous or statistical health information that does not, either by itself or when combined with other information available to the holder, permit individuals to be identified." Similarly, Ontario's PHIPA defines "personal health information" in section 4 as "…identifying information about an individual… ."

[17] HIA para. 1(1)(i) and 1(1)(k); HIPA para. 2(m); PHIA ss. 1(1); PHIPA ss. 4(1).

[18] HIPA para. 2(t); PHIA ss. 1(1).

[19] HIA para. 1(1)(f).

[20] PHIPA s. 3.

[21] HIA s. 60 and 61; HIPA Part III, s. 16-22; PHIA Part 3, s. 16-19; PHIPA Part II, s. 10-14.

[22] HIA ss. 22(2); PHIA s.15.

[23] HIPA s. 6; PHIPA s. 8 & 29.

[24] *supra* note 16.

[25] HIA s. 25-27; HIPA s. 26; PHIA s. 21; PHIPA s. 37.

[26] HIA s. 27.
[27] HIPA para 27(4)(g); PHIA ss. 21(d).
[28] PHIA s. 24; PHIPA s. 44.
[29] Although Warren and Brandeis are frequently cited in the literature as starting points for modern discussions of privacy, James Fitzjames Stephen, an English jurist and philosopher, offered a fuller explication of privacy some seventeen years earlier in his work entitled *Liberty, Equality, and Fraternity*. This paper cites the reprinted version of the Warren and Brandeis article contained in Schoeman's anthology on the philosophical dimensions of privacy. The original article appeared in the *Harvard Law Review, 4(193)*.
[30] Although Warren and Brandeis wrote in the context of a 19th century controversy over the publication of details and photographs from the wedding of one of Warren's daughters, their work remains relevant today, evidenced partly by the fact that the original article was included in the privacy anthology edited by Schoeman in 1984.
[31] Narrow privacy rights are the static symbolic protections that defend the conception of human dignity in Neill's ontology by making manifest the obligation that symbolizes that dignity. These narrow rights are thus safeguarded by natural, conventional static norms.
[32] Wilkinson (2004) has concluded that Canadian legislation is best characterized as protective of personal data protection rather than privacy. For this reason, she opines that confidentiality, rather than privacy, may provide the more felicitous conceptual framework for interpreting personal data protection legislation in this country.
[33] cf. PIPEDA preamble and the stated purpose of Part 1 (Protection of Personal Information in the Private Sector).
[34] It should be noted that the raw data provided by this survey have been used by the consulting company contracted by the Government of Canada only to compute initial descriptive statistics that outline frequencies of opinion for each question on a stand-alone basis. Prior to this paper no attempt has been made to conduct deeper analysis that would test for relationships and associations between different variables.
[35] All tests were run using SPSS 11.0 at an alpha level of 0.05, unless otherwise stated.
[36] s*upra* note 17.
[37] Authors such as Priscilla Regan (Regan 1995, 1996) and Judith Wagner deCew (Wagner DeCew 1997, 2000) have discussed the implications of using health information in the context of employment and insurance decisions.
[38] The survey instrument did not specify the context in which scientific researchers work but contrasts them with "health care companies" engaged in research and development – so respondents can be fairly presumed to have been thinking of "scientific researchers" in a public sector context when responding to these questions.
[39] The wording of this question asked respondents about the "privacy of personal information" in general, rather than specifying medical or genetic privacy.
[40] The Leaders' Forum Steering Committee, which was formed in 2003 by the Council for Health Research in Canada, is a partnership comprised of major federal and provincial government research agencies, teaching hospitals, regional health authorities, health research institutes, universities, health charities, scientific societies, industry, health professionals, and research advocacy organizations.