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Personal health information in Canada: A comparison of citizen expectations and legislation

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Abstract

This paper explores whether the Canadian legislative protections in place to safeguard medical privacy meet the expectations of Canadians. An overview of current governance systems designed to protect the privacy of personal health information at both the federal and provincial levels is first presented. This is followed by an empirical analysis of the results of a public opinion survey conducted to determine Canadian attitudes about medical privacy, particularly genetic privacy. The analysis highlights areas where legislation and public opinion converge and diverge.

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1. Introduction

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 (Appelbaum, 2002; Canadian Institutes of Health Research, 2002; Gellman, 1999). This is particularly the case with regard to genetic information, which, according to some authors, merits even stricter protection (Annas, 1998; Annas, Glantz, & Roche, 1995). In Canada, the federal government has enacted legislation designed to protect personal information in the commercial sphere, and four provinces have promulgated information

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protection legislation specific to the healthcare sector, which would appear to respond to a premise prominent in the literature that people consider medical data to be a sensitive type of personal information. This paper seeks to expand on this theme by mapping the results of an analysis of a public opinion survey about medical and genetic privacy to relevant federal and provincial privacy protection legislation. Section 2 of the paper will be devoted to a brief 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. Having established the legislative terrain, Section 3 of this paper will discuss the empirical findings in respect of public opinion concerning medical and genetic privacy, including areas where current legislation meets or fails to satisfy the desires of Canadians.

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 & Rotenberg, 1997; Bennett & 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

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. However, it was not until April 13, 2000, when the *Personal Information Protection and Electronic Documents Act*

¹ cf. Flaherty, D. (1972). *Privacy in colonial New England*. Charlottesville: University of Virginia Press, who 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, includes a discussion of 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.

(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 (EU), 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, ¶ 8). In a decision from December 20, 2001, the EU Commission stated that Canada’s PIPEDA did meet the required standard set out by the EU Data Protection Directive (European Commission, 2001). Thus, the PIPEDA achieved the objective of ensuring that EU 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

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 should be pointed out that Quebec adopted private sector personal data protection legislation in 1993, which became effective in 1994 (Comeau & 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*, S.S. 1990–91, c. F-22.01, in 1990. Manitoba assented to its *Freedom of Information and Protection of Privacy Act*, S.M. 1997, c. 50, C.C.S.M. c. F175, in 1997, which replaced *The Freedom of Information Act*, S.M. 1985–86, c. 6. Ontario passed its *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F.31, in 1987. 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*, S.N.B. 1998, c. P-19.1, was passed. Prince Edward Island passed its *Freedom of Information and Protection of Privacy Act*, S.P.E.I. 2001, c. 37, in 2001. Nova Scotians are protected by their provincial *Freedom of Information and Protection of Privacy Act*, S.N.S. 1993, c. 5, passed in 1993. 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*, S.N.L. 2002, c. A-1.1, went into force in January of 2005. The Northwest Territories and Nunavut are protected by the *Access to Information and Protection of Privacy Act*, S.N.W.T. 1994, c. 20, passed in 1994 and which went into effect on December 31, 1996. Under Section 76.05 of the *Nunavut Act*, S.C. 1993, c. 28, 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*, S.Y. 1995, c. 1, which was proclaimed on July 1, 1996. This Act was repealed and replaced by R.S.Y. 2002, c. 1.

⁵ Section 91(2) of the *Constitution Act, 1867* (U.K.), 30 & 31 Vict., c. 3, reprinted in R.S.C. 1985, App. II, No. 5, which confers responsibility for inter-provincial trade and commerce upon the federal government, is often referred to as the so-called “commercial clause.”

PIPEDA into what otherwise might be considered provincial jurisdiction.⁶ 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. As defined by the PIPEDA in subsection 2(1), “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.” 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 has 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 *Personal Health Information Protection Act*⁸ has been recognized as being “substantially similar” (Canadian Department of Industry, 2005).⁹ 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

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 *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5 [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 *Personal Health Information Protection Act*, 2004, S.O. 2004, c. 3, Sch. A [PHIPA].

⁹ Although Alberta’s *Health Information Act*, R.S.A. 2000, c. H-5 [HIA], has not been recognized as being “substantially similar,” the province’s broader *Personal Information Protection Act*, S.A. 2003, c. P-6.5, has been deemed equivalent to the PIPEDA. Therefore, the healthcare sector must abide by this latter Act until the former is recognized as being “substantially similar.”

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 1996.¹⁰ 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 personal information may be collected, used, or disclosed. The form of consent may, however, vary depending upon the type of information and the circumstances of its collection, use, or disclosure.¹¹ Sensitive information should normally only be collected with the express consent of the data subject, while implied consent is usually acceptable for less sensitive information.¹² When obtaining consent, organizations should take into consideration the reasonable expectations of the individual to whom the information pertains.¹³ 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.¹⁴ 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.¹⁵ 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,¹⁶ to comply with a subpoena or warrant, and at the earlier of either 100 years after the record was created or 20 years after the death of the individual to whom the information pertains.¹⁷ Moreover, if these exemptions apply, an organization

¹⁰ The 10 information principles set out in the CSA Code and Schedule 1 of the PIPEDA include the following: 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.

¹¹ PIPEDA, *supra* note 7, s. 7 and Schedule 1, principle 4.3.4.

¹² PIPEDA, *supra* note 7, Schedule 1, principle 4.3.6.

¹³ PIPEDA, *supra* note 7, Schedule 1, principle 4.3.5.

¹⁴ PIPEDA, *supra* note 7, ss. 7(1).

¹⁵ *Id.* at ss. 7(2).

¹⁶ 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.

¹⁷ PIPEDA, *supra* note 7, ss. 7(3).

may disclose personal information for purposes other than those for which it was originally collected.

The 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 statutes specific to the healthcare industry, but only Ontario’s legislation has been deemed “substantially similar.”

2.2. Provincial protection of personal health information¹⁸

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. The Ontario *Personal Health Information Protection Act* (PHIPA) came into force on November 1, 2004. Each of the four acts outlines broadly 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.¹⁹ All four provincial acts apply to identifiable personal health information,²⁰ which includes information about both mental and physical health, including

¹⁸ 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.

¹⁹ HIA, supra note 9, s. 2; *Health Information Protection Act*, S.S. 1999, c. H-0.021 [HIPA], Preamble; *Personal Health Information Act*, S.M. 1997, c. 51, C.C.S.M. c. P33.5 [PHIA], s. 2; PHIPA, supra note 8, s. 1.

²⁰ 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.” The act specifically allows for the collection, use, and disclosure of this type of information for any purpose. 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... .”

genetic information.²¹ All of the acts further specify their scope by outlining who qualifies as a “trustee” (Saskatchewan and Manitoba),²² “custodian” (Alberta),²³ or “health information custodian” (Ontario).²⁴ 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.²⁵

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. In fact, the Act in Alberta includes provisions that permit the collection, use, and disclosure of non-identifying health information for any purpose.²⁶ 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 Saskatchewan and Ontario, consent may be either express or implied, while the acts in Alberta and Manitoba only require that the custodian or trustee take reasonable steps to inform an individual of the purposes for which the health information is being collected.²⁷ Moreover, in Ontario a health information custodian may assume implied consent when collecting information for healthcare purposes.²⁸ All of the four statutes permit trustees or custodians to disclose information to other healthcare providers involved in delivering services to that individual without his consent.²⁹ 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.³⁰ In general, under these acts, personally identifiable health information may

²¹ HIA, supra note 9, para. 1(1)(i) and 1(1)(k); HIPA, supra note 19, para. 2(m); PHIA, supra note 19, ss. 1(1); PHIPA, supra note 8, ss. 4(1).

²² HIPA, supra note 19, para. 2(t); PHIA, supra note 19, ss. 1(1).

²³ HIA, supra note 9, para. 1(1)(f).

²⁴ PHIPA, supra note 8, s. 3.

²⁵ HIA, supra note 9, s. 60 and 61; HIPA, supra note 19, Part III, s. 16–22; PHIA, supra note 19, Part 3, s. 16–19; PHIPA, supra note 8, Part II, s. 10–14.

²⁶ See supra note 20 and accompanying text.

²⁷ HIPA, supra note 19, ss. 6(4); PHIPA, supra note 8, ss. 18(2); HIA, supra note 9, ss. 22(3); PHIA, supra note 19, ss. 15(1).

²⁸ PHIPA, supra, note 8, ss. 20(2).

²⁹ HIA, supra note 9, ss. 35(1); HIPA, supra note 19, s. 27; PHIA, supra note 19, ss. 22(2); PHIPA, supra note 8, ss. 18(2) and s. 38.

³⁰ See supra note 20 and accompanying text.

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.³¹ 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.³² Similar provisions are also found in Saskatchewan's and Manitoba's legislation.³³ 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."³⁴ Manitoba's PHIA and Ontario's PHIPA contain very similar provisions.³⁵ The federal PIPEDA only requires that in cases where information is used or disclosed for research or scholarly purposes without the consent of the individual, that the organization informs the Privacy Commissioner prior to any use or disclosure.³⁶ Also of interest is the fact that the Ontario and Alberta acts, which do define research, draw no distinction between public sector and commercial research.³⁷ Legislation in Saskatchewan and Manitoba does not specifically define research.

³¹ HIA, supra note 9, s. 25–27; HIPA, supra note 19, s. 26; PHIA, supra note 19, s. 21; PHIPA, supra note 8, s. 37.

³² HIA, supra note 9, s. 27.

³³ HIPA, supra note 19, para 27(4)(g); PHIA, supra note 19, ss. 21(d).

³⁴ HIPA, supra note 19, para 29(2)(c).

³⁵ PHIA, supra note 19, s. 24; PHIPA, supra note 8, s. 44.

³⁶ PIPEDA, supra note 7, para. 7(2)(c) and para. 7(3)(f).

³⁷ HIA, supra note 9, para. 1(1)(v); PHIPA, supra note 8, s. 2.

Similar to the statutory requirements in respect of collection and use of personally identifiable health information, 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. All of the acts also allow disclosure without permission for public health purposes, although the drafting in this regard varies between provinces. Alberta's HIA and Saskatchewan's HIPA permit disclosure if the custodian or trustee, as the case may be, has reasonable grounds to believe that such disclosure would minimize danger to the health or safety of any person.³⁸ Manitoba's PHIA allows disclosure without consent in order to prevent a threat to public health or public safety, and Ontario's PHIPA permits disclosure without consent to a medical officer of health or a public health authority.³⁹ Similarly, all four provincial acts allow for disclosure without consent in order to comply with any other provincial or federal enactment, which would include public health protection statutes.

The preceding brief discussion of the major substantive elements contained in the federal PIPEDA and the four provincial acts relating to personal health information provides the backdrop necessary to determine how well these statutory instruments respond to public concerns about the protection of medical and genetic information.⁴⁰

3. Public opinion about issues of medical and genetic privacy

3.1. *Data source and methodology*

The statistical analysis conducted for this paper is based upon the data collected 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.⁴¹ 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 policy makers in Ottawa (Pollara Earncliffe, 2003). Pollara Research and Earncliffe Research and Communications, a leading public opinion and market research firm in Canada, completed the survey on behalf of the BACC. The survey was administered by telephone

³⁸ HIA, *supra* note 9, para. 35(1)(m); HIPA, *supra* note 19, para. 27(4)(a).

³⁹ PHIA, *supra* note 19, sentence 22(2)(b)(ii); PHIPA, *supra* note 8, para. 39(2)(a) and 39(2)(b).

⁴⁰ I have offered a fuller explication and comparison of the both domestic and international privacy instruments elsewhere (Peekhaus, 2006).

⁴¹ 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 the variables examined in this paper.

between February 10, 2003, and February 20, 2003, and included a random sample of 1224 Canadians from all 10 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 Earncliffe and members of the Privacy Working Group of the BACC, was pre-tested on 50 random respondents and refined before being finalized. According to Pollara Earncliffe the pre-test demonstrated a good understanding of the questions. Although the report issued by Pollara does not indicate whether any validity and reliability checks beyond random sampling 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.⁴²

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.⁴³

3.2. Discussion of the findings

The survey instrument solicited responses to a range of questions that spans attitudes about the perceived stringency of current legislation designed to protect various categories of personal information against different actors and organizations to beliefs about the importance of genetic information to future health research and development, including the potential of such information and research to contribute to overall economic growth.

Since the focus of the survey was on genetic privacy, a question was included to determine whether people consider genetic information to be different from other types of medical information such as personal or family medical history. In addition to comparing responses to questions, the following analysis includes a systematic examination of whether attitudes about differences between genetic and other forms of health information lead to statistically significant variations in responses to other survey questions. Given that none of the legislation examined in this paper distinguishes genetic information from other medical information, this analysis promises to yield important evidence about the degree to which the various statutory instruments actually meet the expectations of the populations they were designed to serve. Similarly, a systematic attempt is made to determine whether attitudes about the multiple issues probed by the survey differ significantly across groups

⁴² In a telephone call on March 20, 2006 with Jeff Walker, one of the two people in charge of the survey and who is now with Decima Research in Ottawa, the researcher was assured by Mr. Walker that all attempts were taken to ensure the validity and reliability of the survey instrument and its results, including the pre-testing phase and subsequent refinement of the survey instrument.

⁴³ All tests were run using SPSS 11.0 at an alpha level of 0.05, unless otherwise stated.

based on demographic variables such as age, income, education, and province of residence.⁴⁴ The latter variable is of particular interest given that only three provinces had enacted privacy legislation specific to the healthcare sector at the time of the survey. Significant differences across provinces might provide some insight into why only certain provinces have thought it necessary to promulgate this type of legislation, as well as the extent to which these acts have succeeded in achieving their goals, at least in the mind of their respective publics.

3.2.1. *Genetic information versus other medical information*

The survey posed the following question about perceived differences between genetic information and other types of medical information: “Is it your opinion that genetic information is different from other health information (such as personal medical history or family medical history) or is it essentially the same as other health information?” Although the survey pre-test, according to Pollara Earnscliffe, showed a good understanding of the questions, various respondents may have interpreted the use of the term “different from” in ways that go beyond privacy concerns. For this reason, some caution may be warranted when interpreting the findings associated with this question.

Fifty-three percent 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 demonstrated that this difference is significant ($\chi^2(1, n=1195)=8.88, p<0.05$). 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. Sixty percent 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: $\chi^2(4, n=1224)=60.64, p<0.05$. Although only 67 people (6%) in the sample of 1224 have actually undergone genetic testing, these results could assume increased significance in the future if genetic testing becomes a more common medical diagnostic tool.

The Canadian Biotechnology Advisory Committee (CBAC)⁴⁵ has asserted that, “[u]nlike other information used for health purposes, Canadians feel there is something special about genetic information [sic] that it is not just information *about* us but, because of its uniqueness, it is us” (Canadian Biotechnology Advisory Committee, 2004, p. 1, emphasis in original). This statement neither completely accords with the results from the public opinion survey discussed in this paper, nor does it find wholesale reflection in federal and provincial legislation in respect of personal information.

⁴⁴ In order to keep the paper at a manageable length, discussion focuses mainly on those instances in which statistical findings were discovered.

⁴⁵ The CBAC issues advisory memoranda to the federal and provincial governments of Canada in order to apprise policy makers of issues related to biotechnology that will require immediate or medium term attention as well as the effects of government policy on biotechnological developments in Canada (Canadian Biotechnology Advisory Committee, 2004).

3.2.2. *Benefits and drawbacks of knowing about genetic characteristics*

Respondents were also posed the question: “Is it your opinion that the benefits of knowing more about our genetic information outweigh the drawbacks, or do the drawbacks outweigh the benefits?” While the wording “our genetic information” is somewhat ambiguous, in the context of the survey a reasonable assumption is that people understood this question to refer to their own genetic information. Sixty-three percent of respondents believe the benefits outweigh the drawbacks of knowing more about our genetic characteristics, while 26% think the drawbacks outweigh the benefits ($\chi^2(2, n=1224)=506.09, p<0.05$). The responses to this question were also compared to the demographic variables age, income, education, and province of residence. Age was found to be independent. Those people with at least some university education are more likely than those people with lower levels of education to believe that the benefits outweigh the drawbacks of knowing about genetic characteristics, while people in the latter education category are more inclined to believe that knowing such information would be disadvantageous ($\chi^2(14, n=1224)=43.54, p<0.05$). Although income was found to be associated with beliefs about the relative advantages and disadvantages of knowing about genetic characteristics ($\chi^2(18, n=1224)=65.47, p<0.05$), the only slight pattern that emerged from the residuals analysis was that those people with an annual household income of less than \$35,000 are more likely than those in other income categories to believe that the drawbacks outweigh any benefits of knowing this type of information (a finding that supports the analysis found for the education variable, and which is not completely surprising given that education and income often tend to vary together). Similarly, responses on this question are not independent of province of residence: $\chi^2(24, n=1224)=37.56, p<0.05$. Residents of Ontario ($n=458$) and British Columbia ($n=165$) are more likely than people in other provinces to believe that the benefits outweigh the drawbacks of knowing more about our genetic characteristics, while respondents from Alberta ($n=119$), Saskatchewan ($n=43$), Quebec ($n=287$), and Newfoundland ($n=23$) reported, in greater than expected numbers, that the disadvantages trump the advantages of knowing about our genetic makeup. This finding in the latter province is, again, interesting in light of the research being undertaken using the genetic information of Newfoundland residents. However, it should be noted that the survey was conducted on a national, weighted level so there were only 23 respondents from Newfoundland. Though generalizations cannot be drawn for that province alone, the finding does indicate that further research specific to Newfoundland might yield important research results. Opinions from Manitobans did not deviate substantially from expected responses.

These findings about the advantages or disadvantages of knowing our genetic information are not independent of familiarity with and interest levels in genetic issues. Higher familiarity levels with genetic issues correlate positively with the belief that there are more benefits than drawbacks to knowing about our genetic characteristics. Conversely, people who are unfamiliar with genetic issues are more likely to think that the disadvantages of finding out about our genetic information are greater than any potential advantages ($\chi^2(8, n=1224)=54.01, p<0.05; r_s=+0.11, n=1224, p<0.05$, two-tailed). A similar pattern was found between interest levels in genetic issues and beliefs about the benefits or drawbacks of knowing about genetic characteristics ($\chi^2(8, n=1224)=57.96, p<0.05; r_s=+0.16, n=1224, p<0.05$, two-tailed). People with greater interest in the issue are more likely to see the benefits of knowing about genetic

characteristics, while those with little or no interest are more likely to believe that knowing such information brings more drawbacks than advantages. The analysis also revealed that opinions about the benefits or drawbacks of knowing our genetic characteristics are associated with beliefs about whether genetic information is the same as or different from other types of medical information, although there was no significant correlation found ($\chi^2(4, n=1224)=25.60, p<0.05; r_s=+0.02, n=1224, p>0.05$, two-tailed). Interestingly, those respondents who consider genetic information to be unique are also more likely to perceive more disadvantages than advantages in knowing about our genetic information, which is consistent with other findings about this group of people, who tend to desire strict privacy protection for their genetic information, as will be discussed subsequently. On the other hand, people who think genetic information is essentially the same as other medical information are more likely than expected to believe that the benefits outweigh the drawbacks of knowing more about our genetic information.

At the end of the survey, respondents were asked the exact same question in order to gauge whether opinions had changed over the course of the survey. Indeed, the percentage of respondents who answered that the benefits outweigh the drawbacks of knowing our genetic information increased from 63% to 77%. Those who thought such knowledge brought more disadvantages decreased by 8%, from 26% to 18%, and the “don’t know/refused” category dropped from 12% to 5%. Of the people who originally answered that the benefits outweigh the drawbacks, 6% (68) reversed their position and 1% (15) changed their answer to “don’t know/refused.” Among the respondents who originally believed that the drawbacks outweigh the benefits of knowing our genetic characteristics, 14% (173) completely switched their answer and 1% (14) changed their response to “don’t know/refused” by the end of the survey. Among those respondents who initially did not know or gave no answer, by the end of the survey 7% (87) thought that the benefits outweigh the drawbacks and 2% (27) thought that the drawbacks outweigh the benefits. In general, by the time the survey concluded more people were likely to adduce advantages to knowing our genetic information than was the case at the beginning of the survey: $\chi^2(4, n=1224)=246.94, p<0.05$. In terms of the residuals among the provinces, substantial changes were noted only for Saskatchewan ($n=43$) and Manitoba ($n=46$), where, the second time around, people were more likely than expected to believe that the benefits outweigh the drawbacks of knowing about our genetic characteristics.

The fact that people with higher levels of interest in and familiarity with genetic issues tend to believe that advantages attach to knowing about our genetic characteristics bodes well for the Canadian Biotechnology Strategy, which seeks to exploit genetic research as a driver for future economic growth and development.⁴⁶

⁴⁶ The Government of Canada first adopted a National Biotechnology Strategy in 1983, which was subsequently refocused and transformed into the Federal Regulatory Framework for Biotechnology in 1993. The latest iteration, the Canadian Biotechnology Strategy (CBS), was developed in 1998 to address a broader range of issues in respect of biotechnology. According to the CBS Web site, the goal of this strategy is to promote “the scientifically-sound development, application and export of biotechnology through strategic investments that: modernize the regulatory system; support cutting-edge R&D; increase access to investment capital; strengthen Canada’s intellectual capital; engage Canadians directly in shaping relevant policies; create highly qualified human resource capacity; and update patent laws” (<http://www.biostrategy.gc.ca/english/View.asp?x=520>, accessed July 15, 2006).

3.2.3. Organizational treatment of personal information

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 (such as credit rating or spending habits) 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: $F_r(3, n=1224)=370.37, p<0.05$.

The differing responses to these questions about the organizational treatment of different types of personal information were compared against the variables age, income, education, and respondents’ province of residence. In respect of the latter variable, province of residence, 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 exhibiting less apprehension about how their medical and genetic information is handled. However, no significant differences across provinces were detected. With respect to the other demographic variables, significant, though not very strong, correlations were found only between income and levels of concern about the way each type of personal information is handled by organizations. The Spearman correlations between concern about the way different types of personal information is treated and income varied between +0.13 for financial information, +0.10 for communication habits information, +0.07 for medical information, and +0.06 for genetic information ($n=1224, p<0.05$, two-tailed for all tests). As incomes increase, so too do levels of concern about the way organizations handle the different categories of personal information. It is interesting to note that the correlations were strongest for financial information and weakest for genetic information, which might indicate that the federal PIPEDA has yet to completely allay people’s fears about divulging personal information when transacting with commercial enterprises. Recent revelations about lost or stolen client financial information from Talvest Mutual Funds (a subsidiary of Canadian Imperial Bank of Commerce), TJX Companies Inc. (which owns Winners and Home Sense), and Club Monaco will, no doubt, serve to exacerbate such concerns. Similarly, one might speculate that the relatively low rank attributed to concerns about genetic information might change as issues surrounding genetic testing assume increased prominence in public debate.

Keeping in mind that the correlations for all types of personal information were not particularly strong, these findings, nonetheless, seem to contradict the results of some previous surveys, which have indicated that although those respondents with greater levels of education and income are not usually concerned about privacy in general, they tend to be more concerned about the protection of their health information than those on the lower end of the sociodemographic scale (Bennett & Raab, 2006). Westin has interpreted such results in the following manner:

It may be that such respondents feel capable of defending their informational interests quite well in the employment and consumer contexts, and feel a part of the governing elite as far as general privacy concerns are involved. But, their use of mental health services and their adverse medical confidentiality experiences make them feel sensitive-and vulnerable-when medical and health information is involved (as cited in Bennett & Raab, 2006, p. 66).

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 (60% of those surveyed claimed to be either “somewhat” or “very 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: $\chi^2(16, n=1224)=41.20, p<0.05$. 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: $r_s=+0.11, n=1224, p<0.05$, two-tailed. The correlation increased only minimally among those respondents who believe there is a difference between genetic and other forms of medical information: $r_s=+0.12, n=649, p<0.05$, two-tailed. The correlation did not achieve statistical significance among those people who consider genetic information to be essentially the same as other types of health information. Overall, these findings may well indicate that 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, particularly if such an increased awareness leads more people to view genetic information as being different from other types of medical information. That having been said, some caution should be exercised when interpreting these results, which could reflect broader Canadian attitudes to organizations that also happen to keep medical and genetic information, rather than specifically to the issue of privacy.

3.2.4. *Beliefs about the stringency of laws to protect personal information*

As might be expected, given their reactions in the areas just discussed, a relatively low number of respondents believe that the laws and regulations pertaining to the treatment of communication habits information (31%) and financial information (39%) are “somewhat” or “very 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 holds 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: $F_r(3, n=1224)=276.95, p<0.05$. Chi-square tests demonstrated that for all four types of information, attitudes about how concerned respondents are about organizational treatment of their various types of personal information are not independent of participants’ beliefs about the stringency of the laws that regulate the way these sorts of personal information are handled: medical information $\chi^2(16, n=1224)=116.34, p<0.05$; genetic information $\chi^2(16, n=1224)=125.26, p<0.05$; financial information $\chi^2(16, n=1224)=107.80, p<0.05$; and communication habits information $\chi^2(16, n=1224)=93.22, p<0.05$. In general, those respondents who claim to be more concerned about the way their various types of personal information are treated by organizations are also more likely to doubt the stringency of laws designed to protect those types of information.

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 either “not very” or “not at all 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.

While the analysis revealed that opinions about the stringency of laws that regulate genetic information are not independent of opinions about whether there is a difference between medical and genetic information ($\chi^2(8, n=1224)=16.25, p<0.05$), the practical significance of this finding is limited given that the analysis of residuals failed to reveal a discernible pattern. Similarly, it was determined that attitudes about the stringency of laws governing medical information are independent of beliefs about whether genetic information differs from other health information.

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 three provinces had enacted medical privacy legislation at the time the survey was conducted, a reasonable assumption might be that there is a relationship. This assumption was confirmed, although the correlations were weak: $r_s=+0.09, n=1224, p<0.05$, two-tailed for attitudes about the stringency of laws regulating medical information and province of residence; $r_s=+0.08, n=1224, p<0.05$, two-tailed for attitudes about the stringency of laws regulating genetic information and respondents’ province of residence. Respondents from Alberta ($n=119$), Saskatchewan ($n=43$), New Brunswick ($n=31$), and Newfoundland ($n=23$) are more likely than expected to believe that the regulatory regimes in place to protect medical information are “very stringent.” People in Quebec ($n=287$) and Manitoba ($n=46$) think more times than expected that laws to protect medical information are either “very” or “somewhat stringent,” while Ontarians ($n=458$) are more likely to believe, and certainly more than in any other province, that the rules protecting medical information are either “somewhat” or “very lax.” It should be reiterated that Ontario had not yet enacted its *Personal Health Information Protection Act* at the time of the survey. It would be very interesting in future research to determine whether attitudes have since changed among Ontario residents.

Opinions across a number of provinces were different in respect of beliefs about the stringency of governance systems for genetic information. People in New Brunswick ($n=31$) and Ontario ($n=458$) are more likely to believe that the laws to protect genetic information are “very lax.” Similarly, in Alberta ($n=119$), Saskatchewan ($n=43$), and Manitoba ($n=46$) there are higher numbers of people than would be expected in the general population who believe that the regulation and protection of genetic information is “somewhat lax.” These inter-

provincial discrepancies in respect of opinions about the stringency of laws in place to protect medical and genetic information are most interesting for the four provinces that have enacted privacy legislation specific to the health sector, given that all of the acts offer the same statutory protection to both types of information.

3.2.5. *Regulating access to genetic information*

Gostin (1995) has argued, from a practical point of view, that unique protections for genetic information in the healthcare setting could adversely affect record keeping and information flow because organizations would have to apply different practices to some of the health data they maintain if such data were to meet the definition of genetic information. Similarly, there exist other health conditions, such as HIV and mental illness, which might be considered just as sensitive as genetic information (Gostin, 1995). Nonetheless, 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: $\chi^2(1, n=1191)=45.58, p<0.05$. There is not, however, a statistically significant association between attitudes about how strictly to regulate access to genetic information and province of residence: $\chi^2(24, n=1224)=33.79, p>0.05$.

A chi-square test of independence confirmed that attitudes about how strictly access to genetic information should be regulated as compared to other health information are not independent of beliefs about whether genetic information is different from other types of health information: $\chi^2(4, n=1224)=89.96, p<0.05$. Those respondents who consider genetic information to be different from other health information are more likely to believe that access to the former should be more strictly regulated than access to the latter. 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. 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.⁴⁷

It was also determined that attitudes about whether access to genetic information should be regulated more strictly than access to other types of health information are associated with perceptions about the stringency of laws in place to protect the confidentiality of genetic information: $\chi^2(8, n=1224)=26.61, p<0.05$. Those respondents who think that access to genetic information should be more strictly regulated are more likely than those who would regulate genetic and other health information in an equivalent manner to believe that the current laws and regulations that protect the privacy of genetic information are either “somewhat” or “very lax.” Conversely, those who would regulate genetic information the same way as other medical information tend to think that current governance regimes are “somewhat” or “very stringent.”

⁴⁷ supra note 21.

Of those respondents who believe that access to genetic information should be more strictly regulated than access to other health information, 52% also think that the medical and research community should play the main regulatory role, while 44% want the government to assume the main role ($\chi^2(4, n=1224)=58.35, p<0.05$). 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 (58%), 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 (39%). One might therefore 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 warrants stricter regulation tend to favor the medical and research community as the watchdog for the protection of genetic information. An analysis of these two variables by province demonstrated that the association maintained statistical significance for Quebec ($n=287$), Ontario ($n=458$), Alberta ($n=119$), and British Columbia ($n=165$).

When comparing responses to these two variables based upon attitudes about whether genetic information is different from other types of medical information, the analysis determined that among those respondents who posit a difference between these two types of information, feelings about how strictly to regulate access to genetic information and who should play the main regulatory role are not independent of one another: $\chi^2(4, n=649)=15.94, p<0.05$. Conversely, responses to these two questions were independent of one another among those respondents who consider genetic information to be essentially the same as other medical information: $\chi^2(4, n=546)=8.98, p>0.05$. In other words, people who think that genetic information is different from other types of medical information are more likely than those who see no difference between these categories of health information to want access to a person's genetic data more closely guarded and prefer the government, rather than the medical and research community, to provide that guardianship role. Overall, this tendency to prefer governmental oversight of the regulatory systems designed to protect genetic information lends support to the decision by Alberta, Saskatchewan, Manitoba, and Ontario to promulgate legislation that specifically safeguards health information, including genetic information.

3.2.6. *Family members and genetic testing*

The survey revealed 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. Thirty-seven percent do not think that an obligation arises. These differences were found to be statistically significant: $\chi^2(1, n=1197)=68.81, p<0.05$. This result reinforces the claim made by [Anita Allen \(1997\)](#) that family members might have a moral right to be informed of a relative's genetic information that affects

them. It was also ascertained that attitudes about informing family members of test results are not independent of opinions about whether genetic information is different from other medical information: $\chi^2(4, n=1224)=13.52, p<0.05$. Those respondents who think that genetic information is different tend less often to believe that they have an obligation to inform family members of test results that may affect them than is the case among those people who see no difference between the two types of health information. These findings are interesting given that the legislation in place to protect medical information does not impose an obligation on individuals to share their genetic information with family members.

The survey also asked respondents whether family members should have the right to say they do not want to know about the results of a test the respondent has undergone, even if those tests reveal information that could affect the family member. Overall, 86% of respondents either “agreed” or “strongly agreed” with this right for family members to decline being informed. However, those respondents who believe they have an obligation to inform family members of test results that may affect them were found to be much more likely to disagree with the right of family members to say they do not want to be informed. Conversely, those people who do not feel an obligation to inform family members are much more likely to support the right of family members to refuse being informed of genetic information that might have implications for them in the future ($\chi^2(8, n=1224)=22.57, p<0.05$). It would appear that those people who desire greater autonomy in respect of their scope for making personal decisions are more likely, as might be expected, to confer this same level of decisional autonomy on family members. Opinions about whether family members should have the right to not be informed of genetic test results were found to be independent of attitudes about whether genetic information is essentially the same or different from other types of health information. Unfortunately, the survey did not pose a question about whether the individual who submits to genetic testing should be afforded the right to decide not to be informed of the results. Nor is this issue taken up by the provincial or federal statutes considered in this paper.

3.2.7. Professional and organizational access to genetic information

The growing breadth and complexity of medical record keeping practices, coupled with access demands to medical information by a growing range of actors external to the healthcare sector, have made it increasingly difficult for physicians to rely on traditional ethical guidance about how to treat patient information (Gellman, 1984). Not only is more information being captured in medical records, but expanding numbers of non-medical actors are seeking access to this information. It is for this reason that the American privacy expert, Robert Gellman, argued, as early as 1984, that appropriate legislation is required. Indeed, as one observer colorfully notes, “[d]ata is [sic] like a prostitute. Once it’s on the street, everybody has access to it” (Sykes, 1999, p. 101). Part of the dilemma inherent in safeguarding the privacy of medical information stems from the systematic sharing of this information that is systemic to the medical environment. This problem has only been compounded in recent years as medical treatment migrates, in part, outside of the traditional environment to the realm of complementary and alternative medicine. As more actors become

involved in healthcare, the potential for data leakage increases, as does the possibility that information will be shared without the consent and/or knowledge of the individual to whom it pertains.

In this vein, 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. Respondents were not provided with prompts or a list of possible benefits and drawbacks. 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: $F_r(7, n=1224)=3384.82, p<0.05$. Chi-square tests for each person and organization, all of which were statistically significant using an adjusted alpha level of 0.0063,⁴⁸ revealed large positive residuals; that is, there were more observed counts than expected counts of people who think 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 think the drawbacks outweigh 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, people believe that the benefits outweigh the drawbacks in allowing the actors traditionally involved in healthcare delivery to access their genetic information. Conversely, people are skeptical of the potential for any benefits that might come from allowing employers, insurance companies, and governments to access to their genetic information. Overall, these findings reflect 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 regard to government access since all of the acts provide exemptions 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

⁴⁸ As mentioned previously, the alpha level for all tests was set at 0.05, meaning that the possibility of a Type I error (incorrectly rejecting the null hypothesis) was reduced to no more than one in twenty chances. When more than one statistical test is computed, the chance of finding at least one test to be statistically significant increases, when, in fact, the result is due to chance fluctuation in the total experiment. In five tests the probability of finding at least one significant difference or relationship due to chance fluctuation equals 0.22, or one in five. Using the Bonferroni method, the alpha level of each individual test is adjusted downwards to ensure that the overall experiment-wise risk for a number of tests remains at 0.05. Even though more than one test was run, by using the adjusted alpha level of 0.0063, the risk of finding a significant difference or effect due only to chance remained at 0.05.

among respondents change if government access is limited, as it is in the federal and four provincial acts.

Analysis was also conducted to determine whether opinions about allowing these various medical professionals and organizations access to genetic information are associated with respondents' beliefs about whether genetic and other types of health information are the same. People who consider genetic information to be different from other medical information are more likely to believe that the drawbacks outweigh the benefits of permitting all types of medical professionals and organizations access to their genetic information.

These results illustrate an aspect of health information protection legislation that does not satisfy public opinion. 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. Yet, as discussed in Section 2 of this paper, all of the provincial acts permit disclosure without consent to other health practitioners. Based upon these survey results, it might be concluded that the various access exemptions included in all the statutes, as outlined in Section 2, do not sit well with a significant portion of the Canadian public.

3.2.8. *Genetic information and insurance*

A number of questions in the survey dealt specifically with whether insurance companies should be allowed access to an applicant's genetic information in order to assess a person's risk of future health problems. These questions dealt at a broad level with insurance coverage in general rather than asking about specific types of coverage such as supplemental health, disability, or life insurance. An overwhelming 90% of respondents are opposed to such a right (a result which, as might be expected, is statistically significant: $\chi^2(1, n=622)=418.17, p<0.05$). 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 firms could not obtain this information, 86% and 83% of respondents, respectively, would still prohibit this type of access. Chi-square tests determined that these results are statistically significant: $\chi^2(1, n=1073)=619.04, p<0.05$, for the possibility that insurance companies would be exposed to major financial risks, and $\chi^2(1, n=1064)=545.72, p<0.05$, when asked to consider the possibility that premiums would increase across the board if insurance companies were denied access to genetic information. Responses to these questions were also compared to respondents' beliefs about whether genetic information is different from other types of medical data. The question about whether possible exposure to major financial risk for insurance companies should warrant these enterprises being permitted to access genetic information was found to be statistically independent of beliefs about the uniqueness of this type of information ($\chi^2(4, n=1103)=6.74, p>0.05$). However, opinions about whether insurance companies should be permitted access to genetic information in the first place ($\chi^2(4, n=632)=13.79, p<0.05$), as well as if opinions would change if all premiums increased as a result of non-access ($\chi^2(4, n=1103)=2172, p<0.05$), were found to be related to respondents' perceptions about whether medical and genetic

information are different from one another. Given that an overwhelming majority of respondents would preclude insurance companies from accessing genetic information, the residuals for these chi-square tests were quite small. Nonetheless, they did demonstrate that those people who consider genetic information to be different from other types of medical information are even more likely than others to want to keep the former category of information beyond the reach of insurance companies. Analysis also showed that there were no significant correlations between the questions asking about insurance company access to genetic information and the demographic variables income, education, age, and province of residence.

Although insurance companies fall beyond the scope of organizations permitted by the four provincial acts examined in this paper to access personal medical information, there is currently no Canadian legislation in place that specifically treats the possibility of genetic discrimination in the context of private insurance contracts. There are also no legislative barriers to prevent insurance companies from requiring genetic testing as a condition for obtaining life or supplemental health insurance coverage.

3.2.9. *Genetic information and employment*

Statistically significant results were also 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 ($\chi^2(1, n=1202)=841.96, p<0.05$). The residuals for this question were quite large, meaning that significantly more people than expected would preclude employers from accessing genetic information than is the case in the general population. Chi-square tests revealed that opinions about whether employers should be allowed to request genetic information from employees are associated with respondents' age, education, income, and province of residence: $\chi^2(12, n=1224)=21.42, p<0.05$ for age; $\chi^2(14, n=1224)=173.43, p<0.05$ for education; $\chi^2(18, n=1224)=63.94, p<0.05$ for income; and $\chi^2(24, n=1224)=61.67, p<0.05$ for province of residence. In general, people either over the age of 24, or who have a college diploma or higher level of education, or who have an annual household income greater than \$35,000 are all more likely than expected in the general population to be opposed to granting employers the right to ask for genetic information. Although the majority of respondents would not allow employers the right to ask for this information, analysis of the residuals indicated that people in Saskatchewan ($n=43$), Ontario ($n=458$), New Brunswick ($n=31$), and Nova Scotia ($n=38$) are more likely than expected to accord employers this right. As might also be intuited, given some of the previous results, those people who think that genetic information is different from other types of medical information tend to be more opposed to allowing employers access to genetic information than is the case among those who do not consider this type of information to differ from other health information ($\chi^2(4, n=1224)=63.24, p<0.05$). These concerns about employer and insurance company access to personal genetic information are reflected in the four provincial health information protection acts, all of which place these institutional actors beyond the scope of the definition of health information “custodian” or “trustee.”

3.2.10. Genetic information and research

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.⁴⁹ Seventy-three percent (438) of respondents believe that scientific researchers should be permitted access, while 22% (134) would prohibit access, despite an individual's consent. Among those 22% (134) of respondents who would not allow access, even with consent, 66% (89) would change their mind if their names were completely removed from the genetic information being used. In comparison, only 47% (287) of respondents are willing to give healthcare companies access to genetic information. Of the 49% (299) who would not allow healthcare companies to access genetic information, 53% (159) would change their mind and allow access if names were completely removed from the research database. Opinions about allowing healthcare companies access were found to be independent of attitudes about whether genetic information is different from other forms of medical information ($\chi^2(4, n=614)=4.10, p>0.05$). However, it was determined that opinions about giving researchers access to genetic information are associated with beliefs about whether this type of information differs from other health information: $\chi^2(4, n=598)=9.68, p<0.05$. Those who think genetic information is unique tend to be less willing to grant researchers access to this information than are those respondents who consider genetic information to be the same as other medical information.

These two variables were also compared against the demographic variables age, education, income, and province of residence. Opinions about allowing scientific researchers access to genetic information were found to be independent of age and province. However, associations were found between this variable and income ($\chi^2(18, n=598)=51.87, p<0.05$) and education ($\chi^2(14, n=598)=53.57, p<0.05$). No clear pattern emerged from the residuals of the income variable, but from the analysis of education it was clear that those respondents with a college diploma or higher level of schooling are more likely to be in favor of giving scientific researchers access to their genetic data than would be expected in the general population. The only significant demographic variable associated with opinions about permitting healthcare companies access to genetic information was age, for which there was also a moderately low Spearman correlation: $r_s=+0.25, n=614, p<0.05$, two-tailed. In general, people over the age of 45 are less likely than younger age cohorts to allow healthcare companies access to their genetic information.

In this survey, it was assumed in these particular questions about access for research purposes that the individual 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

⁴⁹ It should be pointed out that the two questions about allowing researchers and healthcare companies access to genetic information have, respectively, 626 and 610 unexplained missing values. These missing data preclude chi-square analyses of the differences in attitudes about allowing access to genetic information between scientific researchers and healthcare companies.

care companies, and so on) access to their genetic information would rise. Since the PIPEDA and all four provincial health information protection acts provide exceptions for using personal health information without consent for research purposes, as discussed in Section 2 of this paper,⁵⁰ it may be presumed that these exceptions would be opposed by many in the population. Despite some of the limitations of the survey wording, 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.⁵¹

3.2.11. *Using genetic information for future research*

Respondents were asked if scientific researchers or companies that have developed health research databases should be able to use contributed genetic samples for other research studies if they have the consent of sample contributors. Sixty-three percent agreed and 34% disagreed that researchers and companies should have this right. Aside from being double-barreled, this particular question seems to imply a blanket consent that is somewhat confusing. It would be very illuminating in a future study to ascertain whether people's opinions would be different without the consent caveat included in the question. Nonetheless, a chi-square test for goodness of fit demonstrated that these differences are statistically significant: $\chi^2(1, n=549)=47.22, p<0.05$. A further chi-square test showed that responses to this question are not independent of respondents' beliefs about whether genetic information is different from other categories of medical information: $\chi^2(4, n=567)=13.28, p<0.05$. Although more people on both sides of the debate about the difference between genetic and other medical information would permit the use of genetic samples in further research projects, the residuals of the chi-square test indicate that those individuals who consider genetic information to be distinctive are more likely to permit the use of samples in additional health research studies than those who consider genetic information to be essentially the same as other medical data. This result seems to contradict all of the other findings determined in respect of the people within this stratum of the sample, who generally desire strict protection of their genetic information.

When compared to the variables age, income, education, and province of residence, only education and income were found to be statistically associated with opinions about whether genetic samples should be used for additional research. Though there was no clear pattern for the income variable ($\chi^2(18, n=567)=37.03, p<0.05$), the association with education indicated that respondents with at least some university or greater are more

⁵⁰ PIPEDA, supra note 7, s. 7; HIA, supra note 9, s. 50; HIPA, supra note 19, s. 29; PHIA, supra note 19, s. 24; PHIPA, supra note 8, s. 44.

⁵¹ 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 it seems reasonable to presume that respondents would have been thinking of "scientific researchers" in a public sector context when responding to these questions. In future research it would be valuable to determine whether the willingness of people to contribute their health information to research projects differs depending upon whether the study is conducted by either commercial enterprises or by public sector researchers.

likely to believe that genetic samples should not be used for additional research projects ($\chi^2(14, n=567)=62.33, p<0.05$).

3.2.12. *Selling genetic information*

The previous results were roughly reversed for the question whether researchers and companies should be permitted to sell the information derived from genetic samples contained in their databases to others engaged in research studies if they had the consent of sample contributors. Thirty percent of respondents answered “yes” and 68% said “no”, which are significant results: $\chi^2(1, n=645)=94.59, p<0.05$. This variable is independent of the variables age, education, and income, though not of province of residence ($\chi^2(22, n=657)=48.52, p<0.05$). The residual analysis for this question by province was rather interesting in that the residuals were almost evenly split between positive and negative values. Nonetheless, in the overall question the majority of respondents is opposed to allowing researchers and companies the right to sell the genetic information in their databases. Those people who believe genetic information is different from other types of medical information are more likely to object to selling genetic information contained in research databases while those who consider genetic information to be essentially the same as other health information are more likely to agree to such sales ($\chi^2(4, n=657)=16.85, p<0.05$).

Of the four provincial acts examined in this study, only Manitoba’s *Personal Health Information Act* (Section 27) explicitly prohibits the sale of personal health information, except in the case of the sale of a healthcare practice from one “trustee” to another. Nonetheless, the other three provincial statutes all require consent before personally identifiable health information may be disclosed to a non-custodian or non-trustee, as the case may be, unless the information is being used for purposes consistent with the delivery of healthcare or management of the provincial healthcare delivery system.⁵² Thus, current legislation in Alberta, Saskatchewan, Manitoba, and Ontario would appear to meet the expectations of Canadians that their health information not be used for purposes inconsistent with healthcare delivery, unless they have provided explicit consent. Schedule 1 of the PIPEDA generally requires that an individual provide knowledgeable consent before his personal information may be collected, used, or disclosed, except where inappropriate. Moreover, Principle 5 of PIPEDA’s Schedule 1 requires that personal information may only be used or disclosed for purposes consistent with those that gave rise to the original collection, unless the information subject provides consent. It would therefore appear that federal legislation would preclude the sale of genetic information without the permission of the person to whom it pertains.

3.2.13. *Who should regulate genetic privacy?*

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

⁵² HIA, supra note 9, s. 34 and 35; HIPA, supra note 19, s. 27; PHIA, supra note 19, s. 22; PHIPA, supra note 8, ss. 18(3).

(41%) should play the main role in regulating the privacy of genetic information in Canada. This difference is statistically significant: $\chi^2(1, n=1176)=28.79, p<0.05$, with the residuals demonstrating that significantly more people than expected would entrust the medical and research community rather than the government with protecting genetic privacy. However, as mentioned previously, among those respondents who believe that genetic information is different from other types of medical information and that the first should be regulated more strictly than the latter, there is a statistically significant tendency to favor government rather than medical community oversight of genetic privacy ($\chi^2(4, n=1224)=27.43, p<0.05$). Those who consider genetic information to be the same as other medical information follow the majority in entrusting the protection of genetic privacy to the medical and research community. Opinions about who should assume the main regulatory role for genetic privacy are independent of age but not of education ($\chi^2(14, n=1224)=140.96, p<0.05$), income ($\chi^2(18, n=1224)=72.93, p<0.05$), or province of residence ($\chi^2(24, n=1224)=38.42, p<0.05$). Respondents in Newfoundland ($n=23$), New Brunswick ($n=31$), and Quebec ($n=287$) are more likely than expected to want the government to assume the main regulatory role for safeguarding genetic privacy, while people in Nova Scotia ($n=38$), Prince Edward Island ($n=8$), Alberta ($n=119$), and British Columbia ($n=165$) would entrust the medical and research community with this role. It seems somewhat peculiar that of the provinces with specific legislation to protect the privacy of health information, only Alberta demonstrated a discernible pattern, and in this case it was support for the medical and research community rather than for the government as the main regulator of genetic information. People who have at least some university education tend more often than expected to want the government to regulate and ensure genetic privacy, though below some university education no consistent pattern among the residuals could be detected. Similarly, an analysis of the residuals among the income variable failed to discern any clear patterns. Thus, upon closer examination it does appear that there is substantial support among the population for governments to assume a role in safeguarding the privacy of personal genetic information.

3.2.14. *Government priorities in respect of genetic information*

A battery of eight questions asked survey participants to rank in importance a series of potential priorities for government to consider with regard to genetic information. A Friedman test demonstrated that the differences in the rankings articulated by respondents for each possible priority are statistically significant: $F_r(7, n=1224)=1032.04, p<0.05$. Respondents attributed the highest level of importance to strictly protecting the privacy of genetic information, followed by developing cures to disease, preventing discrimination in the workplace based on genetic information, regulating appropriate access to genetic databases, monitoring the various uses of personal genetic information, working with other countries to develop common rules and regulations regarding genetic information, ensuring Canada is not left out of the economic benefits that come with research and development in genetics, and promoting Canadian leadership in genetics research and development. Respondents who believe that genetic information is different from other types of medical information rank these priorities in the same order as found in the overall sample. People who do not consider genetic information to be different reversed the order slightly and ranked finding cures to disease as the

top government priority, followed by strictly protecting genetic privacy. In general, these results support the other findings, discussed above, that demonstrate those people who view genetic information as being unique also desire more rigorous protection for this type of medical information. Perhaps most interesting is the prominence attributed to the strict protection of genetic privacy, something that all the acts examined in this research study attempt to balance in one way or another with competing government and private sector interests.

3.3. Building an explanatory model

Given the differences in responses to various questions throughout the survey based upon beliefs about whether genetic information is essentially the same as or different from other types of health information, an attempt was made using logistic regression⁵³ to explain what might predict a respondent's answer to this question. An initial hypothesis was that demographic variables such as age, income, education, and province of residence might help predict whether a respondent would consider genetic information to be the same as or different from other types of health information. Indeed, these are the only variables from the survey that made sense to employ when constructing an explanatory model. However, the logistic regression model developed was not statistically significant, implying that beliefs about the nature of genetic information vis-à-vis other health information cannot be determined on the basis of any of these variables. The lack of fit demonstrated by this model is disappointing because it means that no model can be developed, based on the data available, to help predict whether people will view genetic information as essentially the same as or different from other medical information. Given the number of associations found between attitudes on this question and other variables, the prediction capacity of a viable model would have been a useful empirical tool for policy-making processes.

4. Conclusion

It is evident from the preceding analyses of the public opinion survey data that Canadians are, indeed, concerned about the way their personal information is being treated by organizations and regulated by current governance systems. With respect to genetic privacy,

⁵³ Logistic regression is a statistical procedure that can be used to predict a (usually dichotomous) dependent variable on the basis of categorical or continuous independent variables. Logistic regression is also able to determine the amount of variance in the dependent variable explained by the independent variables and to detect interaction effects between the independent variables. The assumptions for logistic regression, which are less strenuous than for ordinary least squares regression, do not require linearity between the dependent and independent variables, normal distribution, or homoscedasticity. Logistic regression does, however, assume independent observations and that the independent variables are linearly related to the logit (log odds) of the dependent variable. Logits, or logit coefficients, are the unstandardized logistic regression coefficients that are usually converted to odds ratios. Odds ratios close to the value 1.0 indicate that the categories of the independent variables and the dependent variable are independent (Hosmer & Lemeshow, 1989; Menard, 2002). This procedure was run using SPSS version 14.0.

the main focus of the survey, Canadians demonstrate an overwhelming interest in the issues associated with this increasingly important branch of science and medical research. There is a tendency among Canadians to voice more concerns about genetics as their knowledge of these issues increases, something that governments across the country may do well to consider as genetic research and development advances. In fact, a slight majority of people believe that genetic information should be more stringently regulated than other forms of medical information.

It was also determined that beliefs about the unique nature of genetic information vis-à-vis other types of medical information have implications for the way Canadians approach the issues associated with genetic privacy. Generally speaking, people of the opinion that genetic information has a distinct character tend to perceive more disadvantages than advantages in knowing about their genetic characteristics and in allowing different people and organizations, including medical professionals, access to such information. This might account for why they also believe that access to genetic information should be more strictly regulated than access to other medical data and that governments, rather than the medical and research community, should be entrusted with safeguarding the privacy of genetic information. Although almost everyone asked would prohibit insurance companies and employers from acquiring genetic information about their clients and employees, people who consider genetic information different from other medical information are even more adamant about this. These people are also less willing to grant health researchers access to their genetic information, believing, in general, that such information will play an only somewhat important role in future health research and development. It is unfortunate that no regression model could be developed using the available data that would help explain why people would consider genetic information to be a distinct type of medical information. Such a predictive tool would have provided further empirical evidence for debate about medical privacy legislation.

It was also found that many of the attitudes in respect of genetic information and privacy, both among the broader population and those who attribute a distinct status to genetic information, deviate in important regards from the current legislative regimes in place to protect medical information. The fact that more people than expected consider current laws in respect of genetic information as too weak might be an indication that citizens want stricter protection than is currently provided for their genetic information built into legislative systems. There were not many questions for which the responses varied significantly across provinces. Indeed, opinions about how strictly to regulate access to genetic information do not vary significantly across provinces. Unfortunately, the other questions for which responses varied by province failed to yield any consistent pattern that might provide empirical data in answer of the question why it is that only the provinces of Alberta, Saskatchewan, Manitoba, and Ontario have promulgated legislation to protect personal medical information. The same general inability to detect consistent patterns among respondents' attitudes about medical and genetic privacy also holds true for the other demographic variables examined in this paper; a result that, no doubt, helps account for the failure of the proposed regression model. Nonetheless, the findings outlined in this paper do support the theme found in much of the literature that people voice concerns about the privacy of their medical information. Moreover, there is some reason to believe that concerns about the privacy of genetic information will

assume increased prominence in the minds of much of the public as the science of genetics and its resulting practical applications expand.

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