

# The Landscape of Rules Governing Access to Personal Information for Health Research: A View from Afar

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*What is asked, or should be asked, of the law student is not that he learn, by heart, and in all their detail, all the rules in force during his time as student: that will be of little service to him in his later professional life when many of those rules will have changed. Of far greater importance to the student will be a knowledge of the structure within which the rules and concepts are organized, the meaning of these categories and concepts, and the relationship of the rules among themselves. The legislators may, indeed, with a stroke of the pen modify the actual legal rules, but these other elements and features nonetheless subsist. They cannot be so arbitrarily changed because they are intimately linked to our civilization and ways of thinking. The legislators can have no more effect on them than upon our language or our reasoning process.<sup>1</sup>*

## Introduction

How can we uphold the individual right of privacy in respect of personal information, while also allow necessary access to that information for *bona fide* health research in order to improve the health of Canadians and their health services? How can we develop a coherent set of norms that respects Canadians' values and strikes a socially acceptable balance between them? How can we ensure that these norms are workable in practice and sufficiently compatible to govern transfers of data across different jurisdictions and/or sectors of activity? Such has been identified as one of the major public policy challenges in the current context of health care reform. The Senate Standing Committee on Social Affairs, Science and Technology recently described the challenge as follows:

The right to privacy and confidentiality of personal health information is a very important value for Canadians. Now more than ever, Canadians need reassurance that their privacy and confidentiality will be respected in this era of rapidly advancing technology. However, the quality of their health and health care is also a value that Canadians cherish very dearly. Health care providers, health care managers and

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<sup>1</sup>René David & John E.C. Brierley, *Major Legal Systems in the World Today*, 3<sup>rd</sup> ed. (London: Stevens & Sons, 1985) at 19.

health researchers need access to personal health information to improve the health of Canadians, strengthen health services and sustain a high quality health care system. The present challenge for Canadians is to set acceptable limits around the right to privacy, on the one hand, and the need for access to information (by health care providers, managers and researchers) on the other, in order to achieve an appropriate balance between them.<sup>2</sup>

Similarly, Commissioner Roy J. Romanow Q.C. echoed these concerns when he articulated the challenge in these terms:

Some might wonder why a chapter on information would figure so prominently and be placed at the beginning of a report on the future of Canada's health care system. The answer is that leading-edge information, technology assessment and research are essential foundations for all of the reforms outlined in subsequent chapters of this report. Furthermore, health research – especially biomedical and scientific research – is an increasingly important component of Canada's knowledge economy and a source of high-skilled, well-paid employment for thousands of Canadians...With better information management and technology in place, researchers can assess the impact and value of different treatments and approaches to delivering health care services in addition to developing and testing new discoveries and cures...Researchers and policy-makers would have access to aggregate data compiled through the electronic health record system. These data could be extracted generically for health research purposes, without being linked to any individual electronic health record. The Commission understands that researchers would, in many cases, prefer to have access to "person-oriented" health information to allow them to track certain illnesses or health-related factors over time. Only when there are sufficient safeguards in place and the system has demonstrated its ability to protect the privacy of individuals, should researchers have access to "person-oriented" data.<sup>3</sup>

Legislation is one possible means for achieving balance between protection of privacy and access to information for research. Like other forms of public policy, legislation has its own advantages and disadvantages. In the current situation, however, legislative reform poses inherent difficulties from the outset. Legislators would not be approaching this challenge with a blank slate. Far from it, there are many existing and proposed laws that vary significantly in their approach and apply

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<sup>2</sup>The Senate Standing Committee on Social Affairs, Science and Technology, *The Health of Canadians – The Federal Role*, vol. 6 (Ottawa: The Senate, 2002) (Chair: The Honourable Michael J.L. Kirby) at 230.

<sup>3</sup>Commission on the Future of Health Care in Canada, *Building on Values: The Future of Health Care in Canada* (Ottawa: Commission on the Future of Health Care in Canada, 2002) (Commissioner Roy J. Romanow, Q.C.) at 75-76, 79.

to discrete — and sometimes overlapping — parts of a larger, rougher landscape. These laws, and the external forces shaping them, need to be analysed and well understood if we hope to smoothen and eventually shift this mass of rules closer towards a desired state of social equilibrium. The purpose of this paper, therefore, is to stand back from a distance to describe the current statutory regime in Canada and discuss some of the underlying reasons or influences behind it. This view from afar will hopefully contribute a different perspective to the ongoing dialogue and assist policy-makers as they consider legislative reform, among other policy options.

## Overview Of Existing Legislation

Statutory instruments governing privacy and confidentiality in the health sector have historically evolved in piecemeal fashion, resulting in an unwieldy hodgepodge of laws and regulations. This reality was observed as early as 1980, when the Hon. Mr. Justice Horace Krever provided an overview of relevant legislation that existed in Ontario at that time:

The legislative treatment of health information is extremely inconsistent. When gathered together, the relevant sections may appear to comprise a formidable body of law. However, in this case, the whole is not greater than the sum of its parts. The whole is merely a collection of piecemeal provisions. No general code is established for the handling of health information. No comprehensive policy is reflected in the present legislation.<sup>4</sup>

To this day, Mr. Justice Krever's observation holds true, not only for Ontario, but for all of Canada.

Of particular interest here are the multitude of statutes regulating access to personal information for health research purposes, as well as the significant variation between them.<sup>5</sup> These statutes emerge from different legal families, take different approaches, have different structures and attempt to address different social objectives.

Constitutional laws protect privacy and confidentiality as fundamental human rights of the individual, subject only to reasonable limits prescribed by law as can be demonstrably justified in a free and democratic society.<sup>6</sup> The Criminal Code

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<sup>4</sup>Royal Commission of Inquiry into the Confidentiality of Health Records in Ontario, *Report of the Commission of Inquiry into the Confidentiality of Health Information*, vol. I (Toronto: Queen's Printer, 1980) (Commissioner: The Hon. Mr. Justice Horace Krever) at 51.

<sup>5</sup>Canadian Institutes of Health Research, *A Compendium of Canadian Legislation respecting the Protection of Personal Information in Health Research*, Patricia Kosseim ed., (Ottawa: Public Works and Government Services Canada, 2000), online: Canadian Institutes of Health Research <[http://www.cihr-irsc.gc.ca/publications/ethics/privacy/compendium\\_e.pdf](http://www.cihr-irsc.gc.ca/publications/ethics/privacy/compendium_e.pdf)>.

<sup>6</sup>*Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982*, being Schedule B to the

makes it an indictable offence to willfully intercept the private communications of others.<sup>7</sup> Privacy statutes in British Columbia, Saskatchewan, Manitoba and Newfoundland & Labrador expressly recognize the existence of a tort, actionable without proof of damage, when a person willfully and without claim of right, violates the privacy of another.<sup>8</sup> Data protection laws recognize the right of persons to have their personal information (or personal health information) protected and the correlative duties on the part of information custodians to ensure respect for that right.<sup>9</sup> Provincial health laws set out consent requirements and regulate various aspects relating to the provision of health care, including the maintenance, confidentiality and management of clinical records.<sup>10</sup> Public health legislation, statistics acts and registry laws govern the collection, use and disclosure of personal information for mandatory reporting, health surveillance and research purposes.<sup>11</sup> In keeping with the Romano-Germanic tradition of codifying general legal principles, the *Civil Code of Québec* expressly recognizes the right to privacy as a personality right, separate and distinct from the recourses that exist under general obligations of contract and civil responsibility.<sup>12</sup>

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*Canada Act*, 1982 (U.K.) 1982, c. 11 [*Charter*], ss. 7-8, in combination with s. 1, as interpreted by the Supreme Court of Canada, *infra* note 35. In Québec, the *Charter of Human Rights and Freedoms*, R.S.Q. c. C-12 protects the right to privacy (article 5) and confidentiality (article 9), subject to proper regard for democratic values, public order and the general well-being of the citizens of Québec (article 9.1).

<sup>7</sup> *Criminal Code*, R.S.C. 1985, c. C-46, s. 184(1).

<sup>8</sup> *Privacy Act*, R.S.B.C. 1996, c. 373; *Privacy Act*, R.S.S. 1978, c. P-24; *Privacy Act*, R.S.M. 1987, c. P-125; *Privacy Act*, R.S.N. 1990, c. P-22.

<sup>9</sup> *Personal Information Protection and Electronic Documents Act*, S.C. 2000, c. 5; *Privacy Act*, R.S.C. 1985, c. P-21; *Freedom of Information and Protection of Privacy Act*, R.S.B.C. 1996, c. 165; *Freedom of Information and Protection of Privacy Act*, S.A. 1994, c. F-18.5; *Freedom of Information and Protection of Privacy Act*, S.S. 1990-91, c. F-22.01; *Freedom of Information and Protection of Privacy Act*, C.C.S.M. F175; *Freedom of Information and Protection of Privacy Act*, R.S.O. 1990, c. F-31; *An act respecting the protection of personal information in the private sector*, R.S.Q. c. P-39.1; *An act respecting access to documents held by public bodies and the protection of personal information*, R.S.Q. c. A-2.1; *Protection of Personal Information Act*, S.N.B. 1998, c. P-19.1 (assented to 26 February 1998, not yet in force); *Freedom of Information and Protection of Privacy Act*, S.N.S. 1993, c. 5; *Access to Information and Protection of Privacy Act*, S.N.L. 2002, c. A-1.1 (assented to 14 March 2002, not yet in force); *Health Information Act*, R.S.A. 2000, c. H-5; *Personal Health Information Act*, C.C.S.M., P33.5; *Health Information Protection Act*, S.S. 1999, c. H-0.021 (assented to 6 May 1999, not yet in force).

<sup>10</sup> See e.g. in British Columbia, *Continuing Care Act*, R.S.B.C. 1996, c. 70, s.11; *Dentists Act*, R.S.B.C. 1996, c. 94, s. 49; *Health Care (Consent) and Care Facility (Admission) Act*, R.S.B.C. 1996, c. 181, s. 4 *et seq.*; *Health Professions Act*, R.S.B.C. 1996, c. 183, s. 53; *Hospital Act*, R.S.B.C. 1996, c. 200, ss. 18, 51 and *Hospital Act Regulation*, B.C. Reg. 121/97, ss. 4(3)(e), 13, 14, 15, 16(2), including Schedule; *Medical Practitioners Act*, R.S.B.C. 1996, c. 285, s. 70; *Medicare Protection Act*, R.S.B.C. 1996, c. 286, ss. 5(1)(p), 5(5), 5(6), 49; *Nurses (Registered) Act*, R.S.B.C. 1996, c. 335, s. 52; *Pharmacists, Pharmacy Operations and Drug Scheduling Act*, R.S.B.C. 1996, c. 363, ss. 35(3), 36, 37, 38, 38.1, 39 and *Access to Pharmacy Patient Record Information Regulation*, B.C. Reg. 384/99.

<sup>11</sup> For a review of relevant legislation in the area of cancer surveillance, see Barbara von Tigerstrom *et al.*, *Use of Cancer Patient Information for Surveillance Purposes: A Systematic Review of Legislation, Regulations, Policies and Guidelines*, Report prepared for the Canadian Coalition on Cancer Surveillance (March 2000), online: Health Canada

<[http://www.hc-sc.gc.ca/pphb-dgspsp/ccdpc-cpcmc/cancer/publications/use\\_e.html](http://www.hc-sc.gc.ca/pphb-dgspsp/ccdpc-cpcmc/cancer/publications/use_e.html)>.

<sup>12</sup> *Civil Code of Québec*, S.Q. 1994, c. 64, Arts. 35-41, 1371 *et seq.*

Even within each of these categories of statutes, the scope of application varies significantly. Statutes apply either federally, provincially or territorially. Their scope of application may be extended in some cases by: i) imposing conditions to ensure extra-territorial protection;<sup>13</sup> ii) establishing rules of precedence in the event of conflict with other laws;<sup>14</sup> iii) requiring confidentiality agreements or information-sharing contracts with third parties;<sup>15</sup> or, iv) specifying that organizations must require their employees to take pledges of confidentiality or oaths of secrecy.<sup>16</sup> Some statutes apply to general personal information either in the public sector or private sector; others apply more specifically to personal health information held by a class of specially designated trustees or custodians in the health sector, that includes both public and private organizations.<sup>17</sup>

Statutes further vary in the level of specificity, some remaining at the high level of general principle, others delving into the fine minutiae of detail contained either in the parent statute or in accompanying regulations.<sup>18</sup> Some statutes delegate authority to administrative bodies with broad discretionary powers, while others are much more narrow and prescriptive in the decision-making criteria to be applied.<sup>19</sup>

While the present paper focuses on statutes, it is important to recognize the relationship between statutes and other sources of law that also govern access to personal information for health research purposes, namely, jurisprudence, custom or legal doctrine. The relative importance of different sources of law varies in different legal families. For instance, these other sources of law may actually drive the development of statute, or influence its interpretation and application (such as in the common law tradition). Alternatively, they may be driven by, and essentially give effect to, the general edict of codified principles (such as in the Romano-Germanic tradition).

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<sup>13</sup> See e.g. (Québec) *An act respecting the protection of personal information in the private sector*, *supra* note 9, Art. 17.

<sup>14</sup> See e.g. (Manitoba) *Personal Health Information Act*, *supra* note 9, ss. 4(2), 4(3).

<sup>15</sup> See e.g. (Alberta) *Health Information Act*, *supra* note 9, s. 54(1); (Manitoba) *Personal Health Information Act*, *supra* note 9, s. 24(4); (Ontario) *Freedom of Information and Protection of Privacy Act*, *supra* note 9, s. 21(1)(e)(iii) and accompanying regulations R.R.O. 1990, Reg. 460, s. 10(1); (British Columbia) *Medicare Protection Act*, *supra* note 10, ss. 5(5), 5(6).

<sup>16</sup> See e.g. *Statistics Act*, R.S.C., 1985, c. S-19, s. 6(1); *Personal Health Information Regulations*, Man. Reg. 245/97, s. 7.

<sup>17</sup> *Supra* note 9.

<sup>18</sup> Compare the general principles enunciated in the relevant provisions of the *Civil Code of Québec*, *supra* note 12, with the detailed provisions of Ontario's *Freedom of Information and Protection of Privacy Act*, *supra* note 9 and its accompanying regulations R.R.O. 1990, Reg. 460.

<sup>19</sup> Compare the general criteria applied by the Commission d'accès à l'information under s. 125 of Québec's *An act respecting access to documents held by public bodies and the protection of personal information*, *supra* note 9, with the more prescriptive criteria that research ethics boards would have had to apply under s. 45 of Ontario's draft *An act to govern the privacy of personal information*, 2002, online: Ontario Ministry of Consumer and Business Services

<<http://www.cbs.gov.on.ca/mcbs/english/pdf/56XSMB.pdf>>, had the legislation come to pass.

Regulated health professions are governed by professional codes of practice that set out their duty of confidentiality towards their patients; some of these are incorporated into binding regulations, while others are in the form of guidelines.<sup>20</sup> Breach of either could form the grounds for disciplinary proceedings and possibly give rise to a civil action.

For their part, health researchers and institutions must comply with international, national and provincial research ethics guidelines in order to receive public funding and/or regulatory approval for clinical drug trials involving humans.<sup>21</sup> These too, impose relevant requirements that may or may not be statutorily binding,<sup>22</sup> but in any event, could, over time and with customary practice, establish legally recognized norms against which researchers' conduct will be measured in the context of civil proceedings.

Common law and principles of equity continue to protect privacy and confidentiality through remedies for breach of fiduciary duty<sup>23</sup>, breach of confidence,<sup>24</sup> negli-

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<sup>20</sup> In Québec, for instance, professional codes of ethics are incorporated as regulations to the *Professional Code*, R.S.Q. c. C-26, whereas most common law jurisdictions have taken the guideline approach.

<sup>21</sup> See e.g.: *Trials of War Criminals before the Nuremberg Military Tribunals under Control Council Law No. 10*, vol. 2, (Washington, D.C.: U.S. Government Printing Office, 1949) at 181-182, online: Office of Human Subjects Research <<http://ohsr.od.nih.gov/nuremberg.php3>> [*Nuremberg Code*];

World Medical Association, *Ethical Principles for Medical Research Involving Human Subjects*, 18th World Medical Association General Assembly (June 1964, Helsinki, Finland) (amended by the 29th WMA General Assembly, Tokyo, Japan, October 1975; 35th WMA General Assembly, Venice, Italy, October 1983; 41st WMA General Assembly, Hong Kong, September 1989; 48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996; and the 52nd WMA General Assembly, Edinburgh, Scotland, October 2000; Note of Clarification on Paragraph 29 added by the WMA General Assembly, Washington 2002), online: Office of Human Subjects Research <<http://ohsr.od.nih.gov/helsinki.php3>> [*Declaration of Helsinki*];

Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada and Social Sciences and Humanities Research Council of Canada, *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*, (Ottawa: Public Works and Government Services Canada, 1998), online: National Science and Engineering Research Council

<<http://www.nserc.ca/programs/ethics/english/policy.htm>> [*Tri-Council Policy Statement*];

International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use, *Good Clinical Practice: Consolidated Guideline* (Ottawa: Minister of Public Works and Government Services, 1997) (adopted by Health Canada in 1997), online: National Council on Ethics in Human Research, <<http://www.ncehr-cnerh.org/english/gcp/>>.

Plan d'action ministerial en *Éthique de la Recherche et en Intégrité Scientifique* (Québec: Gouvernement du Québec, 1998).

<sup>22</sup> Here again, Québec has codified basic principles in its *Civil Code of Québec*, *supra* note 12, Art. 20 *et seq.*, whereas common law jurisdictions rely mostly on guidelines. A more in-depth comparison of these approaches was carried out in earlier work by the author, Patricia Kosseim, "Non-Therapeutic Research Involving Minors in Common Law Canada and in Québec: Different Forms for Expressing (Different?) Public Policies" (M.A. Thesis, King's College, London, U.K., 1994) [unpublished].

<sup>23</sup> See leading case of *McInerney v. MacDonald*, [1992] 2 S.C.R. 138.

<sup>24</sup> For general principles *Lac Minerals v. International Corona Resources*, [1989] 2 S.C.R. 574; *A.G. v. Guardian Newspapers Ltd. No. 2*, [1990] 1 A.C. 109 (H.L.); *Cadbury Schweppes v. FBI Foods*, [1999] 1 S.C.R. 142. See for an application of principles outside economic or business relationships, see Margaret R. Brazier, ed., *Clerk & Lindsell on Torts*, 17<sup>th</sup> ed. (London: Sweet & Maxwell, 1995) at 1417; Margaret R. Brazier, *The Law of Torts*, 9<sup>th</sup> ed., (London: Butterworths, 1993) at 165; William V.H. Rogers, ed.,

gence,<sup>25</sup> tort of invasion of privacy<sup>26</sup> and infringement of *quasi*-proprietary rights.<sup>27</sup> Established precedents from this case law may eventually find their way into developing legislation.<sup>28</sup>

### Possible External Forces

Viewing Canada's statutory regime from a greater distance reveals some of the external forces that are potentially influencing the multitude and diversity of legislative approaches to privacy. For the purposes of the present paper, the author explores three possible forces that can help explain, in part, the roughness of our existing statutory landscape. These are: 1) the "top-down pressure" of international legal norms; 2) the "push-pull effect" of federal-provincial division of powers; and 3) the "bottom-up groundswell" of consumer demands.

### Top-Down Pressure of International Legal Norms

Be they legally binding or not, international norms have had – and will continue to have – significant influence in shaping the development of national laws.<sup>29</sup> An international comparative study is indispensable for situating Canada's current laws in a more global context and understanding their significance in comparison with others.

Comparative law has a primary role to play in the science of law. It can enlighten the understanding of the place and significance of law by drawing upon the experience of all nations. At a more practical level, it can contribute to the better organisation of international relations by

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*Winfield and Jolowicz on Tort*, 15<sup>th</sup> ed. (London: Sweet & Maxwell, 1998) at 467-468; *Slavutych v. Baker* (1975), 55 D.L.R. (3d) 224 (S.C.C.) at 230; *Argyll v. Argyll*, [1967] Ch. 302; *Stephens v. Avery*, [1988] Ch. 449. See for specific applications in the health sector, *Peters-Brown v. Regina District Health Board et al.* (1995), [1996] 1 W.W.R. 337 (Sask. Q.B.), aff'd (1996), [1997] 1 W.W.R. 638 (Sask. C.A.) and *Mammone v. Bakan, Vancouver Registry*, [1989] B.C.J. No. 2438 (B.C.S.C.) (QL). For duty of confidence as weighed against public health interest see *Re Smith Kline & French Laboratories Ltd.*, [1990] A.C. 64 (H.L.).

<sup>25</sup> See especially *Peters-Brown v. Regina District Health Board*, *ibid.*

<sup>26</sup> Allen M. Linden, *Canadian Tort Law*, 4th ed. (Toronto: Butterworths, 1998) at 52-54; John D.R. Craig, "Invasion of Privacy and Charter Values: The Common-Law Tort Awakens" (1997) 42 McGill L.J. 355; *Krouse v. Chrysler Canada Ltd. et al.*, [1970] 3 O.R. 135, 12 D.L.R. (3d) 463 (H.C.); *Burnett v. The Queen* (1979), 94 D.L.R. (3d) 281 (Ont. H.C.J.); *Caplan v. Caplan*, [1980] 14 C.C.L.T. 191 (Ont. H.C.J.); *Saccone v. Orr* (1982), 34 O.R. (2d) 317 (Co. Ct.); *Roth v. Roth* (1991), 4 O.R. (3d) 740 (Gen. Div.); *Corlett-Lockyer v. Stephens*, [1996] B.C.J. No. 857 (Prov. Ct.) (QL); *Lipiec v. Borsa* (1996), 31 C.C.L.T. (2d) 294 (Ont. C.J.); *Dyne Holdings Ltd. v. Royal Insurance Co. of Canada*, [1996] P.E.I.J. No. 28 (C.A.) (QL).

<sup>27</sup> *McInerney v. MacDonald*, *supra* note 23.

<sup>28</sup> A good example of this is the adoption of legislation in four provinces establishing the statutory tort of invasion of privacy, see *supra* note 8.

<sup>29</sup> Although a detailed discussion of international legal norms is beyond the scope of this paper, a more thorough review and analysis can be found in Canadian Institutes of Health Research, *Selected International Legal Norms on the Protection of Personal Information in Health Research*, by Julie Côté & Derek Jones (Ottawa: Public Works and Government Services Canada, 2001), online: Canadian Institutes of Health Research <[http://www.cihr-irsc.gc.ca/publications/ethics/protection\\_pi\\_e.pdf](http://www.cihr-irsc.gc.ca/publications/ethics/protection_pi_e.pdf)>.

showing where agreement is within reach and by suggesting modes of international cooperation. Finally, with respect to national or internal law, it broadens the perspective of those seeking ways to bring about its improvement by inviting them to consider new ideas.<sup>30</sup>

The influence of international law on Canada's privacy regime has been felt at the most fundamental level, in helping us define our rights and freedoms as a society, and at the more practical level, in facilitating our participation in global trade through adherence to data protection principles.

### *The Right to Privacy*

The entrenchment of privacy<sup>31</sup> as a fundamental human right finds its source in major international treaties of the post-World War II era. The right to have one's private life protected from unlawful or arbitrary interference, save for compelling reasons of public interest, has been expressly recognized in the *Universal Declaration of Human Rights*,<sup>32</sup> the *European Convention for the Protection of Human Rights and Fundamental Freedoms*<sup>33</sup> and the *International Covenant on Civil and Political Rights*.<sup>34</sup> These international conventions provided the historical backdrop for our *Charter* and its ensuing interpretation by the courts as encompassing the right to privacy under s. 8.<sup>35</sup> More modern international instruments, including the *Convention for the Protection of Human Rights and Dignity of the Human Being with Regard to the Application of Biology and Medicine*,<sup>36</sup> the *Charter of Fundamental Rights of the European Union*<sup>37</sup> and the *Declaration on the Promotion of Patients' Rights in Europe*,<sup>38</sup> will no doubt continue to reinforce the foundational

<sup>30</sup>David & Brierley, *supra* note 1 at 16-17.

<sup>31</sup>For present purposes, "privacy" means the claim of individuals, groups or institutions (against the world) to determine for themselves when, how and to what extent information about them is communicated to others, see Alan F. Westin, *Privacy and Freedom* (New York: Atheneum, 1970).

<sup>32</sup>GA Res. 217 (III), UN GAOR, 3d Sess., Supp. No. 13, Doc. A/810 (1948) 71 at Art. 12, online: Office of the High Commissioner of Human Rights <<http://www.unhcr.ch/udhr/lang/eng.htm>>.

<sup>33</sup>4 November 1950, 213 U.N.T.S. 221, Eur. T.S. 5 at Art. 8, online: Council of Europe <<http://conventions.coe.int/Treaty/EN/cadreprincipal.htm>>.

<sup>34</sup>19 December 1966, 999 U.N.T.S. 171, Can. T.S. 1976 No. 47, 6 I.L.M. 368 (entered into force 23 March 1976) at Art. 17, online: Office of the High Commissioner of Human Rights <[http://www.unhcr.ch/html/menu3/b/a\\_ccpr.htm](http://www.unhcr.ch/html/menu3/b/a_ccpr.htm)>.

<sup>35</sup>These international sources were considered by the Supreme Court of Canada in *Edmonton Journal v. Alberta (A.G.)*, [1989] 2 S.C.R. 1326 at 1377-78; *R. v. O'Connor*, [1995] 4 S.C.R. 411. The right to privacy has been read into the *Charter* and is now regarded as a constitutionally-entrenched human right in Canada, see *Hunter v. Southam Inc.*, [1984] 2 S.C.R. 145; *R. v. Dymnt*, [1988] 2 S.C.R. 417; *R. v. Duarte*, [1990] 1 S.C.R. 30; *R. v. Plante*, [1993] 3 S.C.R. 281; *R. v. Colarusso*, [1994] 1 S.C.R. 20; *R. v. Mills*, [1999] 3 S.C.R. 668.

<sup>36</sup>4 April 1997, E.T.S. 164 at Art. 10, online: Council of Europe <<http://conventions.coe.int/Treaty/EN/cadreprincipal.htm>>.

<sup>37</sup>EC, *Charter of Fundamental Rights of the European Union* [2000] O.J. C. 364/01 at Arts. 7, 8, online: European Parliament <[http://www.europarl.eu.int/charter/pdf/text\\_en.pdf](http://www.europarl.eu.int/charter/pdf/text_en.pdf)>.

<sup>38</sup>World Health Organization, WHO Regional Office for Europe, *Declaration on the Promotion of Patients' Rights in Europe*, reprinted in 45 *International Digest of Health Legislation* 411 (1995) at Art.

importance of the right to privacy, particularly as it relates to personal health information.

### *The Duty of Confidentiality*

The physician's duty of confidentiality<sup>39</sup> towards his or her patient is rooted in the ancient Hippocratic Oath<sup>40</sup> and has long been recognized at common law as a defining part of the fiduciary relationship between physicians and patients.<sup>41</sup> In the period following the atrocities of World War II, the *Nuremburg Code*<sup>42</sup> and the *Declaration of Helsinki*<sup>43</sup> affirmed fundamental principles of consent and confidentiality in the context of medical research involving humans. These international documents have influenced the development of modern codes of ethics in Canada and around the world, governing not only physicians, but all regulated health professionals, and not only medical researchers, but all researchers conducting research involving humans.<sup>44</sup> Moreover, some provinces have health administration acts in place that now protect the confidentiality of medical records generally, binding all employees of relevant institutions, whether or not they are members of a regulated health profession.<sup>45</sup> Modern international documents, including the *Council of Europe Recommendation on the Protection of Medical Data*<sup>46</sup> and the

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1.4, online: Health Belgium

<<http://www.health.fgov.be/WHI3/periodical/months/wwhv2n1tekst/WWH19019804.htm>>.

<sup>39</sup> For present purposes, "confidentiality" means a duty that arises when information is communicated in the context of a special relationship where the information is intended to be held in confidence or kept secret, from *Black's Law Dictionary*, 5<sup>th</sup> ed., s.v. "confidentiality".

<sup>40</sup> "... What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about..." Ludwig Edelstein, *The Hippocratic Oath: Text, Translation and Interpretation* (Baltimore: The Johns Hopkins Press, 1943).

<sup>41</sup> *Kenny v. Lockwood*, [1932] O.R. 141 (C.A.) at 155; *Henderson v. Johnston*, [1956] O.R. 789 at 799 (S.C.); Ellen I. Picard, *Legal Liability of Doctors and Hospitals in Canada*, 2<sup>nd</sup> ed. (Toronto: Carswell, 1984) at 3; Mark V. Ellis, *Fiduciary Duties in Canada* (Don Mills: DeBoo, 1988) at 10-11; all cited with approval in *McInerney v. MacDonald*, *supra* note 23 at para. 27.

<sup>42</sup> *Supra* note 21.

<sup>43</sup> *Ibid.*

<sup>44</sup> See *Tri-Council Policy Statement*, *supra* note 21.

<sup>45</sup> See e.g. *An Act respecting Health Services and Social Services*, R.S.Q. c. S-4.2, s. 17 *et seq.*

<sup>46</sup> Council of Europe, Committee of Ministers, *Recommendation No. R97(5)*, online: Council of Europe <<http://cm.coe.int/ta/rec/1997/97r5.html>>. See especially s. 3.2:

Medical data may only be collected and processed if in accordance with appropriate safeguards which must be provided by domestic law.

In principle, medical data should be collected and processed only by health-care professionals, or by individuals or bodies working on behalf of health-care professionals. Individuals or bodies working on behalf of health-care professionals who collect and process medical data should be subject to the same rules of confidentiality incumbent on health-care professionals, or to comparable rules of confidentiality.

Controllers of files who are not health-care professionals should only collect and process medical data subject either to rules of confidentiality comparable to those incumbent upon a health-care professional or subject to equally effective safeguards provided for by domestic law.

*European Union Privacy Directive*,<sup>47</sup> reinforce this general expansion of the duty of confidentiality seen in recent decades.

### ***The Freedom of Scientific Research***

The freedom of scientific research and the right to enjoy the benefits of scientific progress are values that have long been recognized internationally. As early as 1948, the *Universal Declaration of Human Rights* enunciated that “(e)veryone has the right freely...to share in scientific advancement and its benefits”.<sup>48</sup>

In 1966, the *International Covenant on Economic, Cultural and Social Rights* recognized the right of everyone to enjoy “the highest attainable standard of physical and mental health”.<sup>49</sup> Accordingly, State Parties undertook to take steps to achieve the full realization of this right, including those necessary for “the prevention, treatment and control of epidemic, endemic, occupational and other diseases” and “the creation of conditions which would assure to all medical service and medical attention in the event of sickness”.<sup>50</sup> Moreover, this same Covenant recognized the “right of everyone to enjoy the benefits of scientific progress and its applications”.<sup>51</sup> Hence, State Parties also undertook to take steps to achieve the full realization of this right, including those necessary for “the conservation, the development and the diffusion of science”, and further undertook “to respect the freedom indispensable for scientific research”.<sup>52</sup>

More recently, since 1997, the *Universal Declaration on the Human Genome and Human Rights* provides that “(f)reedom of research, which is necessary for the progress of knowledge, is part of freedom of thought. The applications of research, including applications in biology, genetics and medicine, concerning the human genome, shall seek to offer relief from suffering and improve the health of individuals and humankind as a whole”.<sup>53</sup>

In contrast, Canada has never formally recognized scientific research as a fundamental freedom. Research is legally regarded here as a public interest exception to the right to privacy and confidentiality; it is not treated as a right or freedom in and of itself, with legal status equivalent to other rights and freedoms. These

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<sup>47</sup> EC, *Directive 95/46/EC of 24 October 1995 on the Protection of Individuals with regard to the Processing of Personal Data and the Free Movement of Such Data*, [1995] O.J. L. 281/31, see article 8(3), online: The European Union On-Line <[http://europa.eu.int/comm/internal\\_market/privacy/law\\_en.htm](http://europa.eu.int/comm/internal_market/privacy/law_en.htm)>.

<sup>48</sup> *Supra* note 32, Art. 27.

<sup>49</sup> GA Res. 2200A (XXI), UN GAOR 21<sup>st</sup> Sess. Supp. No. 16, UN Doc. A/6316 (1966) (entered into force 3 January 1976) at Art. 12(1), online: Office of the High Commissioner of Human Rights <[http://www.unhchr.ch/html/menu3/b/a\\_ceschr.htm](http://www.unhchr.ch/html/menu3/b/a_ceschr.htm)>.

<sup>50</sup> *Ibid.*, Arts. 12(2)(c)-(d).

<sup>51</sup> *Ibid.*, Art. 15(1)(b).

<sup>52</sup> *Ibid.* Arts. 15(2)-(3).

<sup>53</sup> UNESCO OR, 29<sup>th</sup> Sess. (1997), Art. 12(b), online: United Nations Educational, Scientific and Cultural Organization <<http://www.unesco.org/ibc/en/genome/projet/index.htm>>.

different starting points significantly affect the conceptual framework and analysis that policy-makers bring to bear on the issue. From their perspective, Canadian policy-makers afford primary importance to the right to privacy and confidentiality, while acknowledging that there may be some exceptional situations where research, under limited and defined conditions, may be permitted to infringe on the right to privacy and confidentiality. They recognize this exception in the public interest of potentially improving Canadians' health and strengthening the quality and availability of their health care system generally. This approach differs significantly from one that seeks to articulate principles for achieving balance between the right to privacy and confidentiality, on the one hand, and the freedom of research and the right to enjoy the benefits of scientific advancement, on the other, whereby each of these rights and freedoms are placed on an equal legal footing.

### *Data Protection Principles*

It is particularly in the area of data protection where international law has greatly influenced Canada's statutory regime in recent years.<sup>54</sup> The emerging body of data protection legislation stems from increasing regulation of international trade. In 1980, the Organization for Economic Cooperation and Development (OECD) adopted Guidelines on the *Protection on Privacy and Transborder Flows of Personal Data*.<sup>55</sup> Though non-binding, the OECD Guidelines established the basic framework of eight data protection principles<sup>56</sup> that would be emulated in data protection laws around the world, including Canada's public sector legislation.

In 1995, the European Union adopted a *Privacy Directive* obliging Member states to bring their national laws in compliance with the principles of the Directive within three years.<sup>57</sup> Furthermore, Article 25(2) of the Directive obliges Member States to provide in their national laws that the transfer of personal data to third countries may take place only if the third country in question ensures an "adequate level of protection". This obligation prompted Canada, the U.S., Australia and other non-EU countries to adopt national laws with adequate level of protection in order to continue to benefit from commercial trade with Europe that involves transfer of personal data. In the case of Canada, the *Personal Information and Electronic Documents Act* was adopted and entered into force, in part, as of January 1, 2000.<sup>58</sup> In an opinion issued by the *Working Party on the Protection*

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<sup>54</sup>For present purposes, "data protection" means a series of organizational requirements aimed at protecting the personal information of individuals.

<sup>55</sup>OECD, *Guidelines Governing the Protection of Privacy and Transborder Flows of Personal Data*, (1980), online: Government of Poland <[http://www.giodo.gov.pl/Docs/Foreign\\_Docs/Miedzynar/rek\\_rady\\_OECD.htm#1](http://www.giodo.gov.pl/Docs/Foreign_Docs/Miedzynar/rek_rady_OECD.htm#1)>.

<sup>56</sup>These eight data protection principles are: 1) Collection Limitation; 2) Data Quality; 3) Purpose Specification; 4) Use Limitation; 5) Security Safeguards; 6) Openness; 7) Individual Participation; and 8) Accountability.

<sup>57</sup>*Supra* note 47, Art. 32(1).

<sup>58</sup>S.C. 2000, c. 5 [*PIPEDA*]. For a discussion on the application of *PIPEDA* in the health research context, see Canadian Institutes of Health Research & Canadian Institute for Health Information, *Personal Information Protection and Electronic Documents Act: Questions and Answers for Health Researchers*

of *Individuals with regard to the Processing of Personal Data* established under Article 29 of the Directive, *PIPEDA* was considered as providing an “adequate level of protection”.<sup>59</sup> This opinion was confirmed in a formal decision of the European Commission dated December 20, 2001:

The Canadian Act covers all the basic principles necessary for an adequate level of protection for natural persons, even if exceptions and limitations are also provided for in order to safeguard important public interests and to recognize certain information which exists in the public domain. The application of these standards is guaranteed by judicial remedy and by independent supervision carried out by the authorities, such as the Federal Privacy Commissioner invested with powers of investigation and intervention. Furthermore, the provisions of Canadian law regarding civil liability apply in the event of unlawful processing which is prejudicial to the persons concerned.<sup>60</sup>

In a trickle-down effect, *PIPEDA* provides that, as of January 1, 2004, Part I of the Act will apply to any organization that, in the course of commercial activity, collects, uses or discloses personal information *within* a province, unless the Governor in Council is satisfied that there already exists in that province, substantially similar legislation that applies to that organization.<sup>61</sup> In this way, *PIPEDA* creates an incentive for provinces to adopt substantially similar legislation in order to seek an exemption before the stipulated date. Industry Canada recently issued a public notice indicating the criteria it will apply when determining whether a province’s or territory’s private sector legislation will be deemed substantially similar to *PIPEDA* pursuant to subparagraph 26(2)(b). Substantially similar legislation will be expected to:

- incorporate the ten principles in Schedule 1 of *PIPEDA*
- provide for an independent and effective oversight and redress mechanism with powers to investigate;
- restrict the collection, use and disclosure of personal information to purposes that are appropriate or legitimate.<sup>62</sup>

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(Ottawa: Public Works and Government Services Canada, 2001), online: Canadian Institutes of Health Research <[http://www.cihr-irsc.gc.ca/publications/ethics/privacy/intro\\_qa\\_e.shtml](http://www.cihr-irsc.gc.ca/publications/ethics/privacy/intro_qa_e.shtml)>.

<sup>59</sup> EC, Data Protection Working Party, *Opinion 2/2001 on the Adequacy of the Canadian Personal Information and Electronic Documents Act*, [2001], online: The European Union On-line <[http://europa.eu.int/comm/internal\\_market/privacy/docs/wpdocs/2001/wp39en.pdf](http://europa.eu.int/comm/internal_market/privacy/docs/wpdocs/2001/wp39en.pdf)>.

<sup>60</sup> EC, *Commission Decision of 20 December 2001 pursuant to Directive 95/46/EC of the European Parliament and of the Council on the adequate protection of personal data provided by the Canadian Personal Information Protection and Electronic Documents Act*, [2002] O.J. L. 2/13 at 14, online: Eur-Lex <[http://europa.eu.int/eur-lex/pr/en/oj/dat/2002/l\\_002/l\\_00220020104en00130016.pdf](http://europa.eu.int/eur-lex/pr/en/oj/dat/2002/l_002/l_00220020104en00130016.pdf)>.

<sup>61</sup> *PIPEDA*, *supra* note 58, ss. 26(2)(b), 30(1), 30(2).

<sup>62</sup> Notice (Department of Industry), C. Gaz., 2001.I.3618.

At the time of writing this paper, there was still no provincial legislation that had been formally deemed “substantially similar” by Order in Council.<sup>63</sup>

### Push-Pull Effect of Federal-Provincial Division of Powers

Hence, notwithstanding international and national pressures and influences towards greater harmonization, there remains significant variability across provincial laws. This is due, in part, to the countervailing pressures resulting from Canada’s federal-provincial division of legislative powers. For instance, the power to legislate over matters of trade and commerce is conferred exclusively to the Parliament of Canada under s. 91(2) of the *Constitution Act*.<sup>64</sup> The Federal Government used its trade and commerce power when it adopted *PIPEDA* to legislate in respect of personal information that is collected, used and/or disclosed in the course of commercial activity. *PIPEDA* extends its application to both *inter*-provincial and *intra*-provincial flows of personal information, including personal health information.

Yet, the flow of personal information in the health sector straddles both commercial and non-commercial activity. As such, protecting the collection, use and disclosure of personal information in the health sector is necessarily a matter of provincial concern as well. Indeed, the *Constitution Act* confers upon provinces the exclusive power to make laws in relation to the establishment, maintenance, and management of hospitals under s. 92(7), as well as property and civil rights under s. 92(13). Provinces exercise these powers within the confines of their respective jurisdictions, in response to the local pressures of different constituencies and influences of different lobby groups. Provinces are also particularly mindful of their specific economic situation and demographic make-up, which make for unique needs and priorities. As a result, provinces are necessarily driven to regulate in ways that vary from one another.

It is not surprising, therefore, to find different rules scattered widely across the many relevant federal, provincial and territorial laws mentioned above (see: Overview of Existing Legislation). A side-by-side comparison – by jurisdiction and

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<sup>63</sup> In testimony before the House of Commons Standing Committee on Industry and the Senate Standing Committee on Social Affairs, Science and Technology, then Minister of Industry, the Hon. John Manley, stated his belief that Québec’s *Act respecting the protection of personal information in the private sector*, *supra* note 9, would likely be considered substantially similar to *PIPEDA*. To date, however, this has never been formally deemed such by Order in Council. See Canada, House of Commons Committee on Industry, *Evidence* (1 December 1998), online: Standing Committee on Industry <<http://www.parl.gc.ca/InfoComDoc/36/1/INDY/Meetings/Evidence/INDYEV76-E.HTM>>; Canada, Senate Standing Committee on Social Affairs, Science and Technology, *Proceedings* (2 December 1999), online: Senate Standing Committee on Social Affairs, Science and Technology <[http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/soci-e/05cv-e.htm?Language=E&Parl=36&Ses=2&comm\\_id=47](http://www.parl.gc.ca/36/2/parlbus/commbus/senate/Com-e/soci-e/05cv-e.htm?Language=E&Parl=36&Ses=2&comm_id=47)>.

<sup>64</sup> 1982, being Schedule B to the *Canada Act 1982* (U.K.), 1982, c. 11.

sector – of the various conditions under which non-consensual use and/or disclosure of personal information may exceptionally be made for research purposes, alone, illustrates this point.<sup>65</sup> This wide disparity demonstrates how the reality of Canada's federal-provincial division of legislative powers contributes to the existence of many different laws, each with limited scope, applicable to some portion of the health sector, but not others. It also emphasizes that a truly coherent and harmonized policy framework may not be possible through legislation alone. Given the discrete, and parallel apportionment of legislative powers in Canada, legislation needs to be supplemented by inter-jurisdictional cooperation, joint collaborations, agreements in principle, and other creative mechanisms and/or positive incentives towards greater coherence and harmonization.

### Bottom-up Groundswell of Consumer Demands

Yet another, and important, external force influencing the multitude and diversity of existing and emerging legislation is the recent groundswell of consumer demand for privacy. The perceived threat to the individual's ability to control information about themselves appears to have increased in recent years. Several reasons may account for heightened fears, including:

- the increasing commercialization of personal information for marketing purposes;
- media accounts of human and technical fallibilities of health information systems<sup>66</sup>;
- the creation and portability of large databases made possible through rapid advances in information technology;
- the dawn of a genomics era that challenges commonly understood notions of what is or is not anonymous and introduces broader community interests into a concept of privacy that has traditionally been understood as an individual right;
- the globalization of relationships that transforms the individual sense of belonging and responsibility in a well-defined community, into an

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<sup>65</sup> See *A Compendium of Canadian Legislation Respecting the Protection of Personal Information in Health Research*, *supra* note 5 at 5.0-5.25.

<sup>66</sup> "Privacy Commissioner called to assess medical records leak" *The Globe and Mail* (28 May 2002) A8; "SGI hands over private records to researchers" *CBC News* (20 June 2002), online: CBC Saskatchewan Online <<http://www.sask.cbc.ca/archives/privacy/index.html>>; "Trou de mémoire au CHUM, Un incident informatique a provoqué la disparition de 5600 rapports médicaux" *Le Devoir* (25 September 2002) A1, A10.

amorphous world of mass communications where personal and institutional accountability are diffused and boundaries are limitless; and,

- recent threats to public security that have changed the common currency of what were considered appropriate and tolerable infringements of individual privacy.

Recent consumer surveys, particularly in the United States, reveal an increase in consumer concerns about the ability and trustworthiness of organizations to protect their personal information. Alan Westin, a pioneer and leading authority on privacy surveys for over 40 years, reported his latest analysis of more than 120 privacy surveys when he appeared before U.S. Congress last year:

There has been a well-documented transformation in consumer privacy attitudes over the past decade, moving concerns from a modest matter for a minority of consumers in the 1980s to an issue of high intensity expressed by more than three-fourth of American consumers in 2001. In addition, a majority of consumers has become quite privacy assertive in their relations with businesses, making decisions on who to use and what information to provide based on their own privacy judgments. But US consumers also want the benefits of a consumer-service economy, and they are not monolithic in their privacy views...<sup>67</sup>

Westin divided the U.S. public into three segments, each having a very different approach to privacy: 25% represent Privacy Fundamentalists with an especially high concern for privacy issues; 63% are Privacy Pragmatists who believe there should be balance with societal and business needs for information; and 12% (decline from what used to be 20%) are Privacy Unconcerned and have little problem with supplying their personal information to government authorities or businesses.

Canada has conducted considerably less research on the privacy attitudes of consumers. A study conducted by EKOS Research Associates Inc. in 1999 surveyed Canadians' attitudes about privacy and compared their responses to a similar survey conducted in 1992.<sup>68</sup> When asked whether they agree with the following statements:

“I feel I have less personal privacy in my daily life than I did ten years ago”, 47% agreed, compared with 60% in 1992;  
 “There is no real privacy because government can learn anything it

<sup>67</sup>Dr. Alan F. Westin, “Opinion Surveys: What Consumers Have to Say About Information Privacy”, testimony before the House Committee on Energy and Commerce, Sub-Committee on Commerce, Trade, and Consumer Protection, (8 May 2001), online: The House Committee on Energy and Commerce <<http://energycommerce.house.gov/107/hearings/05082001Hearing209/Westin309.htm>>.

<sup>68</sup>EKOS Research Associates Inc., *Rethinking the Information Highway: Privacy, Access and the Shifting Marketplace*, 1999, online: EKOS <[www.ekos.com/studies/highway.asp](http://www.ekos.com/studies/highway.asp)>.

wants about you”, 63% agreed, compared with 81% in 1992; “I feel confident that I have enough information to know how new technology might affect my personal privacy”, 50% agreed, compared with 43% in 1992.

However, of those surveyed in 1999, 54% said that they would want to know about companies’ use of their personal information and have the ability to stop it. Several additional questions further probed their level of agreement with certain uses of personal information for business, government, health, law enforcement and other purposes. Based on these results, the survey does not indicate that privacy has become any less important.<sup>69</sup> Rather, some have suggested that the results indicate Canadians are becoming more sophisticated in their views and attitudes about privacy and may be willing to make certain privacy trade-offs in return for tangible benefits, be they personal or societal.<sup>70</sup> Little is known, however, about those trade-offs, the extent to which, and the conditions under which, Canadians are willing to make them.

These general conclusions are borne out in the context of health research. At a recent CIHR Workshop on “Privacy in Health Research: Sharing Perspectives and Paving the Way Forward”,<sup>71</sup> a panel of experts presented preliminary research findings on Canadians’ attitudes towards the use of their personal information for health research purposes. In sum, their preliminary research suggested that Canadians generally want to participate more actively in the consent process before allowing different research uses of their personal information, but that in some cases, they might be willing to forego a certain degree of their privacy in return for certain health benefits. All agreed, however, that much more rigorous research is needed to better understand the public’s underlying values, their perspectives and their position on policy trade-offs necessary to ensure the protection of personal information, *and* the improvement of health, health services and systems.<sup>72</sup>

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<sup>69</sup>In fact, the number of privacy complaints filed with privacy commissioners seems to be increasing in some jurisdictions. In 2000-2001, the Privacy Commissioner of Canada reported a nearly 10% increase in complaints over the previous year, see Privacy Commissioner of Canada, *Annual Report to Parliament 2000-2001* (Ottawa: Minister of Public Works and Government Services, 2001) at 26, online: Privacy Commissioner of Canada <[http://www.privcom.gc.ca/information/ar/02\\_04\\_09\\_e.pdf](http://www.privcom.gc.ca/information/ar/02_04_09_e.pdf)>. The Information and Privacy Commissioner of Ontario reported an increase of 23% in 2001, compared with 2000, see Information and Privacy Commissioner of Ontario, *Annual Report 2001* (Toronto, Information and Privacy Commissioner of Ontario, 2002) at 29, online: Information and Privacy Commissioner of Ontario <[http://www.ipc.on.ca/scripts/index.asp?action=31&P\\_ID=13161&N\\_ID=1&PT\\_ID=11137&U\\_ID=0](http://www.ipc.on.ca/scripts/index.asp?action=31&P_ID=13161&N_ID=1&PT_ID=11137&U_ID=0)>.

<sup>70</sup>Interpretation provided by the Office of the Privacy Commissioner of Canada, *Annual Report to Parliament 1999-2000* (Ottawa: Minister of Public Works and Government Services, 2000), online: Privacy Commissioner of Canada <[http://www.privcom.gc.ca/information/ar/02\\_04\\_08\\_e.asp](http://www.privcom.gc.ca/information/ar/02_04_08_e.asp)>.

<sup>71</sup>Canadian Institutes of Health Research, *Privacy in Health Research: Sharing Perspectives and Paving the Way Forward*, (Workshop, 14-15 November 2002, Ottawa).

<sup>72</sup>Timothy A. Caulfield & Tim Outerbridge, “DNA Databanks, Public Opinion, and the Law” (2002) 25 *Clin. Invest. Med.* 256; D. Willison, “Consent-Based Registries: If you build them, who will come?” (Paper presented to the Canadian Institutes of Health Research, 14-15 November 2002, Ottawa) [unpublished]; similar conclusions were reached in D. Willison *et al.*, “Patient Consent Preferences for Research

The heightened public demand for privacy and the increasing level of consumer sophistication may constitute yet another force which has prompted governments to adopt privacy legislation in recent years. However, the fact that there is no clear understanding of what Canadians consider acceptable policy trade-offs, and under what conditions, may also explain, in part, the confused and inconsistent legislative approaches we have seen emerge across the country. Meaningful engagement of the public, assurance of their trust, better appreciation and respect for their views, are key for any statutory reform and/or other policy instrument to succeed in striking an appropriate balance of rights and values.

## Conclusion

More often than not, discussion of the current statutory landscape has centred on what the rules are. The tendency to focus on existing laws and to work through all of their intricate details is understandable given the vested commitment of policy-makers to those laws, and the preoccupation of organizations and individuals to fashion their conduct accordingly. Less often does one have the opportunity to stand back from the *status quo*, and analyse *why* those rules are the way they are. In the spirit of comparative legal tradition, this paper has attempted to offer a more distant perspective in order to appreciate the relationships between existing rules and possible reasons for them. It is from this vantage point that one might be better able to see emerge possible options for improvement.

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Uses of Information in Electronic Medical Records: Interview and Survey Data" (2003) 326 Brit. Med. J., online: British Medical Journal <[www.bmj.com](http://www.bmj.com)>; E. Holowaty, "Public Attitudes to Non-Consensual Uses of Personal Information for Cancer Screening and Research", (Paper presented to the Canadian Institutes of Health Research, 14-15 November 2002, Ottawa) [unpublished].

